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ABSTRACT

This report, one of series of reports describing innovative practices in integrating people with disabilities into community life, presents findings and recommendations of a review of the "Supported Housing Demonstration Project", which provides supportive community living services to approximately 32 people with severe physical disabilities in the Pittsburgh (Pennsylvania) area. The review was based on site visits, interviews, and analysis of documents and materials. After an overview of the project's background, the second section looks at program models and practices including use of cluster apartments, a flexible staff role, maximum personal autonomy, and attendant recruitment and screening. The following two sections examine life in the community and interagency collaboration noting the involvement of over 18 private agencies and organizations. Costs are then discussed with lists of start-up, operating, individual, and program support costs and a detailed analysis of costs and funding. The final section presents policy implications and recommendations. These include: that the direction set by the project should be adopted in state and county policy; that a single state agency should lead the planning and coordination of community services for this population; and that a stable long-term funding mechanism is needed to fund the actual costs of supporting people with physical disabilities in the community. Methodology notes are appended. (DB)

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Center on Human Policy

A POLICY ANALYSIS
OF THE SUPPORTED HOUSING
DEMONSTRATION PROJECT

Pittsburgh, PA

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A POLICY ANALYSIS OF THE SUPPORTED HOUSING DEMONSTRATION PROJECT

Pittsburgh, Pennsylvania

by

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This report contains the findings and recommendations of an indepth review of the "Supported Housing Demonstration Project" jointly operated by United Cerebral Palsy Association of Pittsburgh and Three Rivers Center for Independent Living.

The Supported Housing Demonstration Project, formerly called the "Kane Community Services Project," is designed to support people with severe physical disabilities to be able to move from the Kane Regional Centers and other long-term care facilities to the community. Operational since late 1985, the project is intended to enable 32 people with severe disabilities to live in the community.

This review examined the Supported Housing Demonstration Project as a demonstration project. The analysis was directed towards answering the question: What are the lessons of this project for policy regarding people with severe physical disabilities in Pennsylvania and Allegheny County? The review looked at policy issues "from the bottom up." In other words, the review focused on how state and county policies, programs, and funding mechanisms impact on efforts of private agencies to support people with severe physical disabilities in the community.

The report is divided into six major sections:

I. Background of the Supported Housing Demonstration Project.

II. Description of Program Models and Practices: United Cerebral Palsy and Three Rivers Center for Independent Living.

III. Life in the Community.

IV. Agency Commitment and Interagency Collaboration.

V. Funding.

VI. Policy Implications and Recommendations.

This review is based on site visits, interviews, and analysis of documents and materials conducted between October, 1986 and May, 1987. Appendix I summarizes the methodology on which this review is based.

BACKGROUND OF THE SUPPORTED HOUSING DEMONSTRATION PROJECT

The origins of the Supported Housing Demonstration Project stem back to the early 1980's when public officials and private agency representatives began to discuss the possibility of applying for a "Medicaid waiver" for younger, severely disabled people living at the Kane Hospital in Pittsburgh.

A county facility, John J. Kane Hospital was opened in 1958 as a long-term care institution for elderly and physically disabled people. Following negative publicity, including an expose initiated by staff, and a threatened cut-off of federal and state funds for failure to comply with Medicaid standards, Allegheny County moved to close Kane in the 1980s. Around 1983, the Kane Hospital was replaced by four smaller regional centers located in Glen Hazel, Scott Township, McKeesport, and Ross Township, each housing approximately 360 people. The Kane regional centers receive federal and state funds under the Title XIX Medicaid "Intermediate Care Facility" (ICF) and "Skilled Nursing Facility" (SNF) programs.

In 1983-84, United Cerebral Palsy Association of Pittsburgh (UCP) prepared a Medicaid waiver that was submitted by the Pennsylvania Department of Public Welfare (DPW) to the federal Health Care Financing Administration to fund community services for 48 people living in Skilled Nursing Facilities or Intermediate Care Facilities in Allegheny County. Authorized by Section 2176 of the

federal Omnibus Reconciliation Act of 1981, the Medicaid waiver program provides for federal financial reimbursement for home and community-based services offered as an alternative to institutionalization in Medicaid funded facilities. The Commonwealth of Pennsylvania has successfully obtained Medicaid waivers to fund community services for people with mental retardation coming out of state centers.

The UCP/DPW Medicaid waiver was not accepted by the federal Health Care Financing Administration. According to one state official, the waiver had two major problems: (1) a discrepancy between the average stay of people at Kane and the stay of people targeted to be served through the waiver (this was described purely as a "bureaucratic" problem); and (2) the failure to demonstrate a decrease in utilization of SNF or ICF beds as a result of the waiver. No attempt has been made to revise and resubmit the Medicaid waiver.

Although the waiver was not approved, efforts continued to develop a program to support people with physical disabilities to move from Kane and other facilities to the community. With the support of the office of the Allegheny County Board of Commissioners, and especially Commissioner Tom Foerster, and the Governor's Office, UCP joined by Three Rivers Center for Independent Living (TRCIL) worked with a range of state, county, city, and private agencies to fund and establish the Kane Community Services Project.

The Kane project was targeted to people with physical disabilities ages 18 to 59 who lived at Kane or similar facilities

or were at risk of entering a nursing home. The project was designed to be voluntary. Based on assessments conducted by the Kane regional centers, the county Long Term Care Assessment and Management Program (LAMP, part of the Long Term Care Coordination office), UCP, and TRCIL, approximately 140 people at Kane were identified as meeting the project's criteria. According to one document prepared by UCP and TRCIL, 60 of these were identified as having "a good potential for community living."

The design called for 16 people to be supported by UCP and 16 by TRCIL, with the possibility of an additional eight people to be served through the project. In December, 1985, eight people moved into apartments supervised by UCP at Versailles Castle (a large typical apartment complex), while two people supported by TRCIL moved into their own apartments in January, 1986. In September, 1986, UCP moved seven people into apartments at Lindenbrooke Apartments (also a large typical complex) located in the South Park area. Around this time, TRCIL helped eight people move into apartments at Allegheny Independence House.

By March, 1987, TRCIL was supporting 16 people living in their own apartments. UCP supported 15 people living at the Versailles Castle and Lindenbrooke sites. Three people served by UCP have moved back to Kane.

The people served by the Kane project, renamed the Supported Housing Demonstration project in 1986, range in age from the early 20s to late 50s and have a broad range of disabilities, including cerebral palsy, head injury, arthritis, stroke, muscular dystrophy, multiple sclerosis, spinal cord injury, and others.

DESCRIPTION OF PROGRAM MODELS AND PRACTICES:
UNITED CEREBRAL PALSY AND THREE RIVERS CENTER FOR INDEPENDENT LIVING

United Cerebral Palsy and Three Rivers Center for Independent Living have adopted contrasting approaches to supporting people with disabilities in the community.

Like other United Cerebral Palsy affiliates, UCP of Pittsburgh operates a range of residential, day program, and support programs. Established over 35 years ago, major funding for the agency comes from a variety of public and private sources, including state and county contracts and purchase of service arrangements, third party payments for services, United Way funds, and proceeds from fund-raising drives.

UCP of Pittsburgh is marked by a willingness to develop new service models and approaches. In reviewing UCP's programs and the Supported Housing Demonstration Project, one is struck by UCP's ability to get new projects off the ground: to bring together policymakers and providers, to obtain external funds, to solve problems that would stand in the way of most agencies. It is doubtful that the Supported Housing Demonstration Project would ever have gotten beyond the idea stage were it not for UCP's perseverance and tenacity.

Founded in 1980, TRCIL offers a range of independent living, housing, peer support, counseling, and advocacy services and receives core funding from federal and state dollars earmarked for independent living centers. Three Rivers also administers the Attendant Care Program funded by the state Department of Public Welfare. As an independent living center, TRCIL is characterized by

a strong commitment to consumer control, choice, and self-determination. One of the strengths of TRCIL is that approximately half of its staff is composed of people with disabilities.

According to the design of the Supported Housing project, TRCIL supports "higher functioning" people who are capable of making their own decisions, while UCP serves people who have cognitive deficits or limitations in judgment and decision-making. However, meeting people supported by the respective agencies, it is not always apparent that they fall neatly into these categories.

United Cerebral Palsy: Cluster Apartments

For the Supported Housing Demonstration Project, UCP operates and staffs two "clusters," one located at Versailles Castle apartments in North Versailles Township and one located at Lindenbrooke apartments in the Bethel Park area. Each cluster consists of four two-person apartments for clients plus one staff apartment. Through the County IMPAC program, the apartments were renovated to make them accessible to people with mobility impairments. At both clusters, the apartments are interspersed between apartments occupied by nondisabled people.

As of March, 1987, 15 people from Kane and other facilities were living at the two clusters. Three people have returned to Kane due to "medical and psychiatric problems."

The design of the cluster program is that people will move into their own apartments and live more independently as they gain additional skills in community living.

The clusters are both staffed by 12 to 14 full- and part-time staff, in addition to a supervisor who lives at the staff apartment. All of the staff are employees of UCP. During the week,

one part-time staff member works at each apartment from roughly 6:00 A.M. to 9:00 A.M. and one full-time staff member works from approximately 3:00 P.M. to 11:00 P.M., although these hours may vary from day to day. The supervisor is on-call at night from Sunday through Friday and is readily accessible to clients through an intercom system. On weekends, a different complement of staff takes over. As the supervisor is off from Friday afternoon to Sunday evening, two staff sleep over in client apartments (in the living rooms) at each cluster on Friday and Saturday evenings. Additional staff work at the apartments during the day on weekends. At Versailles Castle, each staff member is assigned to an apartment on a permanent basis, although they occasionally fill in for or assist one another, while at Lindenbrooke, they rotate among the four client apartments.

According to staff, they have a flexible role. The role includes counseling, instruction in daily living skills, personal care, cleaning, cooking, assistance in budgeting, meal planning, and shopping, and "any other tasks that are necessary." Staff members report that clients have a major say in such things as food selection, bedtimes, and community activities. They also state that they take clients anywhere they want to go in the community. All clients have a full-day vocational or day program Monday through Friday.

At each cluster, staff take clients grocery shopping every week. One-half the clients go shopping one week and the other half the following week.

Each cluster has its own van, purchased with funds from UCP fund-raising activities, although clients also use the ACCESS door-to-

door transportation service. According to UCP administrators, the agency obtained the vans because ACCESS was too expensive for clients to use on a regular basis.

All clients rent their own apartments. In addition, the clients selected their own furniture and furnishings that was paid for through a grant from the state Developmental Disabilities Planning Council.

Clients also pay for their own food and personal items. Staff members may or may not eat with clients. At Versailles Castle, staff members can share clients' food if "we're invited and there's enough." At Lindenbrooke, staff cannot eat clients' food as a matter of policy.

A review of UCP's operation of the Supported Housing Demonstration Project points to the following strengths of the program:

1. The clusters are located in typical apartment complexes in the community and, hence, afford people with disabilities the opportunity to live alongside nondisabled people. Both the Versailles Castle and Lindenbrooke apartments are attractive and typical looking complexes. By virtue of living at the apartments, UCP clients are visible to community members and, in at least some instances, interact with neighbors and community members who are not disabled.

2. People served through the program are involved in a range of community activities and frequent local grocery stores, shopping centers, and, in many cases, social and recreation centers and churches. UCP clients appear to lead active lives in the community. For example, one person living at Lindenbrooke

apartments has become deeply involved with a local church.

3. The people currently served by UCP receive the necessary supports to meet their programmatic needs and to insure safety. Staff members are available on a routine basis and are accessible in the case of emergencies.

4. People rent apartments in their own names and selected their own furnishings and furniture. This provides a measure of dignity and autonomy unavailable to people living in large congregate settings.

5. UCP has aggressively pursued strategies to enhance the quality of life and increase the degree of community integration of people served through the program. With the support of separate grants from the Pennsylvania Developmental Disabilities Planning Council (DDPC), UCP has initiated "supported work" (to support people in typical jobs in the community) and "community participation" (to help people build relationships with typical community members) projects for people served through the Supported Housing Demonstration Project.

In addition to these strengths, it should also be noted that UCP's administrators and staff working on the project seem competent and extremely committed to the people they serve. As one client put it, "The staff are top notch." In the course of interviewing staff and clients, several examples of staff commitment and dedication were identified. For instance, at Versailles Castle staff aggressively advocated for one person whom they felt was being discriminated against at a day program because she has Hepatitis B. One of these staff members commented, "I'm not going to treat her any different because she has Hepatitis B."

As an agency, UCP has also worked to build staff commitment and sensitivity to the humanity of the people it serves. Staff report that they feel support from UCP and that the agency will provide them with the resources, training, and back-up they need. One staff member stated:

> They've helped us out a lot. . .We've called up and (told them) that we need help. . .And they've been there. Somewhere, somehow the money comes up, from petty cash or somewhere.

A staff member at Lindenbrooke explained how a visit to Kane to meet people prior to their moving into the community built the staff's commitment to the people and their sensitivity to what they have been through. A staff member at Versailles Castle summed up the agency's philosophy: "You have to be mission-oriented, not job-oriented."

While UCP's program is characterized by many strengths, the review of the Supported Housing Demonstration Project identified several policy issues related to the program model that should receive careful attention, especially if the project is expanded in the Pittsburgh area or other parts of the state. First of all, the program is based on a "transition" model. People are expected to move through the program to more independent living as they acquire additional skills. An alternative model is to increase or decrease the amount and intensity of support services as circumstances warrant. Many of these people have already experienced major disruptions in their lives. As a matter of program design, people should have the opportunity to have a stable home if this is what they desire.

Second, UCP's program is an agency-based program, in which staff

are hired and supervised by the agency. While UCP has taken steps to in hiring staff, Some people appear ready and able to hire and supervise their own attendants. The program should be designed to accommodate a range of relationships between clients, on the one hand, and staff or attendants, on the other.

Finally, the program has not been able to accommodate several people who present special challenges by virtue of their medical needs or behavior. To some extent, this is due to the design of the clusters. Since the clusters have four two-person apartments, people who want or need to live alone cannot fit into the program. According to staff, at least two out of the three people who returned to Kane had problems with their roommates which contributed to their moving out. In addition, staff resources and training may need to be adjusted in order for people with more challenging needs to be able to enjoy community living.

Three Rivers Center for Independent Living

Three Rivers uses a "consumer-based" model. People supported through TRCIL live in their own homes and employ their own attendants.

Through the Supported Housing Demonstration Project, TRCIL currently supports 16 people who previously lived at Kane or similar facilities. Approximately one-half of these people live at Allegheny Independence House in Wilmerding, a fully accessible 25-unit apartment house for people with disabilities. Constructed and supported with funding from the Section 202 and Section 8 Housing and Urban Development programs, Allegheny Independence House is owned by TRCIL along with other agencies. The facility has a large community room and has one and two bedroom apartments. Allegheny

House is viewed as a transitional step between Kane and independent living.

Other people supported through the project live throughout the Pittsburgh metropolitan area, primarily in "elderly high-rises." For example, one woman recently moved into Goodwill Plaza in Sheridan, a high-rise for elderly people and those with disabilities.

Most of the people live alone in their own apartments. Several people commented that especially after living at Kane they did not want to have a roommate. However, a couple of people supported through the project live together, while one man lives with his attendant.

Like UCP, TRCIL arranged for people to purchase their own furniture and furnishings through the DDPC grant. The apartments are attractively furnished and equipped with Life-Call/Life-Line emergency systems.

Three Rivers provides two kinds of support to people in the Supported Housing Demonstration Project: arrangement of attendant care and independent living counseling. TRCIL administers the Attendant Care Program in the Pittsburgh area. The agency recruits and screens attendants (although people can also locate their own attendants), refers them to people, and provides assistance and training in attendant management. It also pays for attendant costs. TRCIL pays the person receiving attendant care based on a time sheet jointly signed by the person and the attendant.

People served through the Supported Housing Demonstration Project receive an average of approximately 36 hours of attendant care per week (at $5 per hour), with 70 hours per week the current

maximum. In general, TRCIL expects the number of attendant hours required by each person to decline over time.

People have from one to several attendants. In addition, TRCIL supervises an attendant who works at Allegheny Independence House from 11:00 P.M. to 7:00 A.M. and is available if people need nighttime care and in the case of emergencies.

According to people served through the project, attendants provide a broad range of types of assistance, including personal care, cooking, shopping, writing checks or letters, cleaning, laundry, and other activities.

TRCIL employs independent living counselors and an aide who visit people served through the project daily. Staff help people manage their attendants, provide personal care, assist in money management, write letters for people, and provide related forms of assistance. For a number of people, TRCIL staff members simply stop by to make sure they are doing ok. According to several people supported through the project, just knowing that Three Rivers staff are accessible is important in living on their own. One person explained, "I like the fact that I can call Three Rivers at any time and someone will be here." Another stated:

> There's somebody here every day. They stop in and say, "Hi, how are you doing?" Make sure you're not having any problems.

In contrast to people served through UCP, most of the people supported by TRCIL do not work or participate in day programs. Several people stated that they did not want to do anything during the day, while a couple of people said that they would like to have jobs. TRCIL clients will be eligible for work placements through UCP's supported work project.

As in the case of UCP, TRCIL's program is characterized by a number of strengths:

1. People supported by TRCIL are in control of their lives. The hallmark and greatest strength of TRCIL is its commitment to consumer control and self-determination. People supervise their own attendants and make their own decisions about how they want to live; for example, what to eat, when to go to bed, with whom to live, and many other decisions other people take for granted. This enhances their dignity and self-respect.

2. People selected their own furniture and furnishings with the assistance of TRCIL. Like UCP, TRCIL arranged for people to choose their own furniture and furnishings prior to moving to their homes. The DDPC grant paid for furniture and furnishings.

3. People receive the basic services and supports they require. Between the attendant care and Three Rivers staff, people appear to receive the personal care, assistance in daily living, and guidance they need to live successfully and safely in the community. While a couple of people stated they they could use additional attendant care hours, they believed that their basic needs were being met.

Like UCP staff, TRCIL staff impresses one as being capable and strongly committed to the people they serve. For their part, the people express their deep appreciation for TRCIL and the respect they receive from staff.

Also as in the case of UCP, a review of TRCIL program raises policy issues worthy of careful attention, although some of these issues may be beyond the control of TRCIL.

In the first place, people remain segregated from the community. The majority of people served by TRCIL through the Supported Housing Demonstration Project live at either Allegheny Independence House, a segregated facility, or high-rises for the elderly. They are no longer institutionalized, but they are not part of the community either. Everyone interviewed stated that they were pleased with their lives today as compared to what they were like at Kane. Several also stated that they did not care where they lived as long as they could maintain their own apartments. However, at least some people feel that they are still cut off from the community. One person living at Allegheny Independence House remarked:

> When I was told I would live independently, this isn't what I had in mind. This sort of defeats the purpose.

It should be noted that the construction of Allegheny Independence House and the use of elderly high-rises stems from the shortage of accessible housing in the Pittsburgh metropolitan area, as in most communities around the country. To a large extent, TRCIL has turned to these facilities for people leaving Kane and other institutions because of a lack of options. In terms of future policy directions, however, energies should focus of adapting existing housing for people with mobility impairments.

In the second place, though not to the same degree as UCP in its clusters, TRCIL's program is based on a transition model whereby people are expected to move from Allegheny Independence House into more independent living situations. Referring to Allegheny Independence House, one staff member was quoted in a publication as

follows:

> Our goal is to teach people the skills they need to move out of the complex into individual apartments throughout the community, to integrate the community and stop the segregation of people with disabilities. We'd also like to have some turnover in the building to allow more people the chance to move into what we perceive as a transitional home, where they could get the training and confidence they need to venture out on an independent life.

As noted previously, an alternative perspective is that services and supports should be provided to enable people with disabilities to live independently in integrated community housing.

In the third place, people currently supported by TRCIL through the project do not have sufficient work opportunities or opportunities to participate in typical community activities. This reflects a shortage of supported work programs as well as a lack of accessible public transportation (several people stated that the ACCESS system is inconvenient and expensive given their resources). From a policy standpoint, work options, transportation, and other services must be developed as housing options are created.

LIFE IN THE COMMUNITY

One of the best ways to judge the effectiveness of any social program is the impact on the people it serves as they perceive it. From this vantage point, the Supported Housing Demonstration Project is a tremendous success.

Whether supported by UCP or Three Rivers, <u>the people served through the Supported Housing Demonstration Project have experienced a dramatic increase in the quality of their lives</u>. They are

grateful for the opportunity to live outside of Kane or other institutions. As one person explained:

I wouldn't trade it for anything in the world. I love it here.

The people served through the project seem so happy to be living in the community that they are extremely modest in their expectations of UCP and TRCIL. One UCP staff member commented that clients do not complain about things or ask for anything even when they should. Only one woman, who was supported by UCP, was an exception to this. She stated that she did not like her roommate and complained that she did not go out into the community enough. She also said that she wanted to live in a more independent situation.

None of this is to suggest that the people feel resentful towards Kane or any of its staff. Several people have fond memories of friendships they had with other people at Kane and recalled staff who were kind and caring. When they talk about Kane and how much better their lives are today, they point to problems that are perhaps inevitable in any large-scale institution such as Kane.

While people served through the project like different things about living in the community, a number of themes arose again and again during interviews with them: <u>independence</u>; <u>freedom</u>; and <u>having their own home</u>.

<u>Independence</u>. When asked what people like most about living in the community, a typical response is "Independence." As much as anything else, independence is a state of mind. As one person put it, "Independence is in your heart."

Independence means different things to different people. For some, it means making your own decisions. One person living at

Versailles Castle stated:

> Kane was sheltered. Everything was done for us. We didn't have to make decisions. Here they want us to make decisions.

For other people, being independent means being self-reliant and doing things for one's self. A person supported by TRCIL said:

> This sounds funny, but I enjoy doing the dishes. I don't want somebody standing over me saying you couldn't do it alone. At Kane they want you to be independent but not too independent so you don't need them. One time I was getting into the elevator and a young woman stopped me and said, "Are you sure you're allowed to take the elevator yourself?" Another time I was sitting there and a visitor came in and looked at me and said, "God bless you, you poor crippled thing." That's the kind of thing you had to put up with there.

For still others, the meaning of independence lies in taking responsibility for one's life. As one individual commented:

> What happens to people at places like Kane is that they abdicate responsibility for taking care of themselves. It's always THEY. THEY did it to me so I can't do anything.

A number of people explained that they felt very anxious about leaving Kane and living in the community. They questioned whether they could "make it on my own." One person at Versailles Castle said, "I wanted to see if I could make it on my own."

Many people mentioned that they had friends who were afraid to leave Kane. As they described it, some people were afraid of failing:

> They're scared. They're afraid they won't make it. You have to want it bad to make it work. The nurses will take care of you

there.

*

I had my misgivings, but I wanted to try. People are afraid they won't be able to live on their own. Like what's going to happen to me if I can't leave the bed and no one comes.

They also reported that some people at Kane had become too dependent:

Some people are not too prepared to live independently. They're apprehensive about leaving Kane. They had security, somebody to tell them what to do.

*

I think once they think about coming out and worrying about doing things for themselves they're not going to want to come out and try. And I wanted to. I wanted to. The only way I would know myself is by trying.

*

They didn't want to take responsibility. They had become dependent there on someone doing everything for them.

Freedom. A related theme that emerged during the interviews was "freedom." From the perspective of people who have left Kane and similar facilities, freedom means controlling your own life. Many people stated that as an institution, Kane had many restrictions. One person stated:

There are big differences between this and Kane. Everything was regimented there. Here everything is what I want. I have the freedom to choose. At Kane I was just existing. You have to be in the situation to understand.

When asked what he liked best about living at Allegheny Independence House, one man answered:

> Freedom! If I want to go down the hall I go down there. If I want to go outside I go outside. If I want to come back in I come back in. If I want to go to bed I want to go to bed. If I want to get up I can.

A third person described Kane this way:

> In a word it's an institution. Everything is regimented, very regimented. You have to wait for everything. . .The regimentation was the worst.

One of the people living at Allegheny Independence House explained that whereas at Kane, one could complain about a staff member and maybe that staff member might be reassigned, in her own home she could fire attendants she did not like:

> If they're not doing something right you sit down and talk to them. You tell them the terms. If they don't want to come to terms, then ok, good-bye. Sometimes people don't want to do something and you say, "I'm sorry, then I have to let you go. That's all."

Having Their Own Home. One of the things people like best about the Supported Housing project, especially those supported by TRCIL, is having their own homes--maintaining their own personal space, something that is impossible at an institution. Everyone served by TRCIL who was interviewed pointed out that they set their own household routines, decide what and when to eat, and choose how to spend their time. One person at Allegheny Independence House stated:

> In the institution, my life was lived to their scale. Like

meals were served at certain hours. Everything was geared towards the majority.

Another person said:

> I can cook what I want. I don't have to eat with somebody else. . .I wanted to live alone. I like to watch tv late at night. Some people wouldn't appreciate that. . .At Kane you ate what they cooked and sometimes it wasn't too good. They made spaghetti and meatballs and that was terrible. . .I watch tv. At Kane you had to watch what other people wanted to watch.

A third person commented:

> Here I can have what I want when I want it. I don't have to eat what they make.

Several people talked about how important it was for them to select their own furniture and furnishings and to decorate their own apartments. One woman recalled her first night in her apartment:

> I was awake all night, planning and decorating. I got to do this. I got to do that. I think I feel asleep at 6:00 the next morning.

Another woman said:

> I thought I'd died and gone to heaven. I could buy my own furniture and my own colors and textures.

A number of people pointed out that they could have privacy and quiet in their own homes. Asked what she liked best about living in her apartment, a woman at Allegheny Independence House responded:

> Having my own apartment to do whatever I want to however I want and with whoever I want to and that. The freedom and quietness. In the institution you don't have any quietness. It is quiet here. You're off to yourself in your own place. I

feel it's a complete turnaround.

This woman also explained that it was much easier to have her family visit her in her own apartment since it was her own space. A woman living in an apartment at another location said what she liked best about living in her own apartment:

> The privacy. The ability to shut the door when I want to and not to have nurses always coming in. Not to feel that it's we and they. It was so noisy at night. When I first came here I couldn't sleep because it's so quiet. I laid in bed and listened to the quiet.

A variation on this theme, some people said that one of the most difficult things at Kane was living at a facility with so many sick and dying people. One man stated:

> There were always two people in a room there. I had some real old people who passed away. . .Some of them moaned and groaned and hollared all night. You could hear them all the way down the hall. You don't get that here, hollaring and screaming.

Finally, a woman in her own apartment summed up the experience of living on her own:

> I feel like a human being again, not a number. This may not sound like much, but the first thing I did when I left Kane was take off that dumb bracelet you always had to wear.

AGENCY COMMITMENT AND INTERAGENCY COLLABORATION

That the Supported Housing Demonstration Project exists is a tribute to the efforts of private and public agencies in Pennsylvania and Allegheny County. This is at once the hallmark of the project and its Achilles Heel.

A large number of agencies have come together to operate, fund, and support the project. Over 18 private agencies and organizations and public departments and offices have been directly or indirectly involved in the project:

United Cerebral Palsy of Pittsburgh. UCP of Pittsburgh operates cluster apartments, in addition to day program and supported work services, and has obtained grants used to support clients served by UCP and TRCIL.

Three Rivers Center for Independent Living. TRCIL arranges for attendant care and provides independent living counseling and support to approximately half of the people served through the project. As the administering agency for attendant care, Three Rivers also has a subcontract with UCP for attendant care for people supported through the project.

Long Term Care Assessment and Management Program (LAMP), Allegheny County Office of Long Term Care Coordination. LAMP provides assessment and case management and provides partial program funding to UCP and TRCIL.

Office of Policy, Planning and Evaluation, Department of Public Welfare (DPW). This office funds the state's Attendant Care Program. Created as a demonstration project, the Attendant Care Program was established as a permanent state program in December, 1986. Attendant Care Program funds were earmarked for the Supported Housing Demonstration Project.

Pennsylvania Developmental Disabilities Planning Council. DDPC has awarded four grants that directly or indirectly support the project: start-up funds; supported work, evaluation, community

participation.

Kane Regional Centers, Allegheny County Board of Commissioners. The Kane Centers assisted in the identification and assessment of potential clients.

Allegheny County Housing Authority. This agency administers the Section 8 and Section 202 housing programs. Pittsburgh and McKeesport operate their own housing authorities.

ACCESS, Pittsburgh Port Authority. ACCESS is a subsidized, door-to-door transportation service used by many of the people served through the project.

Allegheny County Adult Service, Area Agency on Aging. This agency, which is an office of the Department of Aging, administers the Domiciliary Care (Dom Care) program that provides financial support to some participants.

Department of Aging. This statewide agency provides funding to LAMP that supports the program.

Office of Vocational Rehabilitation, Department of Labor and Industry. This office administers the independent living center program, which funds TRCIL, awarded a Transition Program grant to TRCIL, and provides grants for adaptive equipment.

Improvement Program of Allegheny County (IMPAC). IMPAC provided grants to make renovations on UCP's cluster apartments.

Forbes Fund of the Pittsburgh Foundation. The Forbes Fund provided interest-free loans to cover people's expenses until they started received their SSI, SSDI, or other income.

Handicapped Challenge Foundation. This foundation provided a grant to TRCIL for start-up costs.

Westinghouse Foundation. This foundation provided start-up

funds for TRCIL.

Department of Public Welfare. This state department administers Medical Assistance and the Supplemental Security Income (SSI) programs.

University of Pittsburgh. Through a grant awarded to TRCIL by DDPC, the University of Pittsburgh Department of Health Services Administration is conducted an evaluation of the Supported Housing Demonstration Project.

Allegheny County Board of Commissioners. The County Commissioners and Commissioner Foerster, in particular, is reported to have played an instrumental role in bringing together public and private agencies to plan and implement the project.

Figure I summarizes the involvement of agencies and organizations in the project.

While many organizations and agencies have supported the Supported Housing Demonstration Project, no single public agency has taken a lead role in planning and coordinating the services for people with physical disabilities. As Human Services Research Institute noted in its 1981 and 1986 policy analyses (Report on the Habilitation Services Objective and A Policy Analysis of Attendant Services in Pennsylvania), no state or local public agency in Pennsylvania is responsible for services for people with severe physical disabilities. By contrast, the Department of Public Welfare's Office of Mental Retardation and Office of Mental Health are responsible for services for people with mental retardation and mental health problems respectively.

FIGURE I

SUPPORTED HOUSING DEMONSTRATION PROJECT

PROGRAM ADMINISTRATION	PROGRAM FUNDING	OTHER SERVICES	GENERAL SUPPORT
United Cerebral Palsy of Pittsburgh	LAMP, Office of Long Term Care Coordination	LAMP, Office of Long Term Care Coordination (Case Management)	LAMP, Office of Long Term Care Coordination
Three Rivers Center for Independent Living	Office of Policy, Planning and Evaluation, DPW	Kane Regional Centers (Assessment)	Allegheny County Board of Commissioners (Commissioner Foerster, in particular)
	Developmental Disabilities Planning Council	ACCESS (Transportation)	
	Department of Public Welfare	United Cerebral Palsy of Pittsburgh (Day Program and Supported Work)	
	Allegheny County Housing Authority (Pittsburgh, McKeesport Housing Authorities)	University of Pittsburgh (Project Evaluation)	
	Allegheny County Adult Service Area Agency on Aging		
	Department of Aging		
	Office of Vocational Rehabilitation		
	Improvement Program of Allegheny County		
	Pittsburgh Foundation		
	Handicapped Challenge Foundation		
	Westinghouse Foundation		
	UCP Fund-Raising Activities		

On the state level in Pennsylvania, three separate state departments administer programs for people with severe physical disabilities (in addition to special education, which is the responsibility of the Department of Education). The Department of Labor and Industry administers the independent living center program and provides funding for vocational rehabilitation and adaptive equipment through the Office of Vocational Rehabilitation. The Department of Aging administers aging block grants and state lottery funds, which in the case of Allegheny County are funneled through the county Office of Long Term Care Coordination. The Department of Aging also administers the Domiciliary Care program and the attendant care program for people 60 years of age and older. The Department of Public Welfare administers the Attendant Care Program through the Office of Policy, Planning and Evaluation, in addition to administering Human Service Development Fund (Title XX) grants, Medical Assistance, and Income Maintenance. In addition, the Pennsylvania Developmental Disabilities Planning Council (DDPC) funds a range of demonstration projects, studies, and similar initiatives.

Recognizing that services for people with physical disabilities are fragmented, with many people denied access, the DDPC recently issued a request for proposal for a "Comprehensive Services Objective." The purpose of the Comprehensive Services Objective is to collect information and design and plan "a coordinated, empowered, generic system of Services."

On the local level in Allegheny County, LAMP of the Office of Long Term Care Coordination provides case management and funds home and community-based services under contract with the Department of Aging.

While the logical agency to plan and coordinate services for people with severe disabilities on the local level, LAMP is limited in terms of resources and currently does not have a clear mandate to provide for alternatives to institutionalization.

Since public agencies lack a mandate for planning and coordinating services for people with severe disabilities, private agencies, specifically, UCP of Pittsburgh and TRCIL, played the lead role in initiating the Supported Housing Demonstration Project. While many agencies and organizations have funded and supported the project, the Supported Housing Demonstration Project would never have been implemented without an extraordinary commitment from UCP and TRCIL. UCP's commitment stems from its entrepreneurial spirit. As one agency official explained:

> We see our role as being at the forefront of services. We have always seen our role as demonstrating new services and new approaches to old services.

For its part, TRCIL is committed to the right of people with disabilities to independent living.

From its start, the Supported Housing Demonstration Project has experienced, and continues to experience, a precarious existence. In the first place, although many public agencies have been involved with the project, the project was established through informal understandings rather than through formal interagency agreements. One state official commented that the project was put together with "bailing wire." An agency administrator stated that it was established through "gentleman's agreements" and "handshakes." At various times, potential funders have backed out of agreements to fund the program. In one instance, a public agency ran out of funds to pay for services

that had been promised. In another instance, a newly appointed agency administrator tried to renege on a commitment made by the previous administrator. A private agency administrator explained:

> We had a good faith agreement. But when the players change, that doesn't mean anything.

In the second place, the project lacks an adequate funding base. As documented in the following section of this report, the costs of the project exceed funding for the project. A slight alteration in the current funding for the project could force the return of people to Kane or other institutions. For example, in the case of UCP's cluster apartments, a potential change in Dom Care regulations could threaten the agency's ability to maintain people in the community.

From a programmatic point of view, the Supported Housing Demonstration Project could easily be replicated in other communities throughout Pennsylvania. Lacking clear-cut public responsibility and an adequate funding mechanism, however, it is doubtful that many communities could implement similar programs, simply because of the amount of energy, resourcefulness, and commitment required to initiate the project. One state official stated:

> I don't know if the project is replicable. You probably couldn't do it anywhere else but Pittsburgh, because Pittsburgh is such a tight-knit and activist community.

FUNDING

Just as the Supported Housing Demonstration Project was established without a clear public mandate--and administrative, planning, and coordinating mechanisms to facilitate the movement of people with severe physical disabilities from institutions to the community, it was developed without a stable funding base to support the effort.

Economics is an salient factor to consider in evaluating any social program. This is not to say that cost considerations outweigh other concerns. To the contrary, any program or public policy should be evaluated first and foremost on the impact on the quality of life of people. It is to say that from a policy standpoint it is important to know how much programs cost and how they are and should be funded.

This review looked at four aspects of the funding of the Supported Housing Demonstration Project: (1) the costs associated with the project; (2) the funding sources used to support these costs; (3) an analysis of costs compared to funding; and (4) a comparison of the costs of the Supported Housing Demonstration Project with the costs of the Kane Regional Centers.

Costs

There is a broad range of costs associated with the Supported Housing Demonstration Project. These costs fall into two major categories. The first is start-up costs; that is, the costs associated with planning and initiating a new program. The second cost category includes operating costs; that is, the costs of supporting people in the community. Within both of these broad categories, costs can be further divided as follows: (1) agency costs (UCP's and TRCIL's costs of operating the programs); (2) individual costs (the expenses incurred by individuals living in the community); and (3) program support costs (costs associated with the project that are incurred by other agencies).

The following is a breakdown of the major costs of the Supported Housing Demonstration Project (whether or not funded by external sources):

Start-Up Costs

Agency (CIL and TRCIL)

Planning (e.g., identification, assessment, and selection of clients; identification of housing; etc.)

Staff Training

Field Office Set-up (for UCP, field office security deposits and phone installation)

Individual

Furniture/Furnishings/Household Goods

Home Modification (e.g., ramps, accessibility)

Adaptive Equipment (e.g., tub lifts)

Security Deposits (e.g., apartments, phone)

Phone Installation (including Life-Call/Life-Line)

Program Support

Assessment of Clients (i.e., for the Supported Housing Demonstration Project, LAMP assisted in the identification of clients)

Operating Costs

Agency (UCP and TRCIL)

Personnel and Fringe (Staff Services)

Agency Administration

Project Director

Controller

Clerical Support

Staff Supervision

Direct Staff Services/Attendant Care

Field Office Rent and Utilities (UCP)

Field Office Phone (UCP)

Staff Development/Training

Staff Travel

Instructional Supplies/Staff Resources

Administrative Overhead (e.g., office rent and utilities)

Administrative Phone

Administrative Postage

Office Equipment and Maintenance

Insurance

Misc.

Individual (Living Expenses)

Rent and Utilities

Phone and Life Call/Life Line

Food

Clothing

Laundry

Personal Expenses

Transportation

Medical Equipment

Adaptive Equipment

Medical/Health Care/Therapy

Program Support Costs

Case Management (LAMP)

Day Program/Supported Work

Transportation

Community Participation (DDPC Grant)

Funding Sources

Funding for the Supported Housing Demonstration Project comes from

a variety of federal, state, county, and private sources. Since the project's inception, 22 separate identifiable funding sources have been used to support the costs of supporting people in the community. The external sources, which directly or indirectly support the project, include: UCP and TRCIL grants and contracts; additional project funding obtained by UCP and TRCIL; individual sources of income, supplements, benefits, and subsidies; and funding for support services. FIGURE II summarizes the major funding sources for the project.

The following is a description of the major sources of funding for the Supported Housing Demonstration Project.

UCP Funding. This includes funds contained in UCP's budget. Major external sources of funding for the Supported Housing Demonstration Project has come from four major sources: (1) LAMP; (2) HSDF; (3) Attendant Care; and (4) DDPC.

LAMP: $76,024.

Through a contract with the Department of Aging, LAMP administers federal and state funds from the Department of Aging and Department of Public Welfare, in addition to providing case management and coordination. For the Supported Housing Demonstration Project, LAMP reimburses UCP at a rate of $13 per person per day. This is in contrast to LAMP's maximum per diem of $27.90. Under the terms of the contract with UCP, LAMP will not pay for the costs of overnight support for UCP clients. UCP's current annual LAMP budget is $76,024. This budget includes the following categories:

1. Personnel:

Direct Care Staff (6)

Benefits

FIGURE II
SUPPORTED HOUSING DEMONSTRATION PROJECT
MAJOR FUNDING SOURCES

Agency Grants and Contracts	Additional Funding Obtained by UCP and TRCIL	Individual Income, Supplements, Subsides, and Benefits	Indirect Funding for Auxiliary Services
UCP	Allegheny County IMPAC Program - UCP Cluster Apartments ($1,500 per apartment in renovations)	Social Security	LAMP Assessment and Case Management
LAMP ($76,024)	Handicapped Challenge TRCIL, 1985-86 ($5,000)	Supplemental Security Income	Human Services Development Fund-UCP (Day Program)
Human Services Development Fund ($38,012)	Westinghouse Foundation-TRCIL, 1986-87 ($5,000)	Domicilary Care Supplement (UCP)	Developmental Disabilities Planning Council Supported Work Grant-UCP
Attendant Care Program ($203,005)	Forbes Fund of the Pittsburgh Foundation, Interest-Free Loan	Section 202/ Section 8	ACCESS Subsidized Transportation
Developmental Disabilities Planning Council Start-up* ($79,819)	Office of Vocational Rehabilitation-Adaptive Equipment ($50,000 per year)	Medical Assistance/ Medicare/Private Insurance	Developmental Disabilities Planning Council Community Participation Grant-UCP
TRCIL** LAMP ($106,627)	UCP Fund-raising 2 Vans ($4,551 depreciation per van)	Food Stamps	
Attendant Care Program ($143,916)			
Office of Vocational Rehabilitation Transition Grant ($20,000)			
Title VII Center for Independent Living Grant ($25,421)			
Department of Public Welfare Start-up Grant ($20,000) first year only)			

* Multiple year funding
**TRCIL also has two independent living center grants that support project administrative costs.

Substitute Staff

2. Operating:

Field Office Rent and Utilities (50%)

Field Office Phones

Office Supplies

Insurance

Staff Travel

3. Administration

Project Director (25%)

Controller (6%)

Fringe on Administrative Staff

HSDF: $38,012.

This is the Human Services Development Fund, funded by the federal Title XX program and administered on the state level by the Department of Public Welfare. The Office of Long Term Care administers HSDF funds for the Supported Housing Demonstration Project. The Office of Long Term Care pays UCP $6.50 per person per day through HSDF funds. For the current fiscal year, UCP's HSDF budget is $38,012. The budget includes:

1. Personnel

Direct Care Personnel (3)

Fringe

2. Operating

Field Office Rent and Utilities (50%)

Attendant Care: $203,005.

These are attendant care funds from the Department of Public Welfare administered by Three Rivers Center for Independent Living. Under a subcontract with UCP, TRCIL provides $203,005

for the Supported Housing Demonstration Project. The budget includes:

1. Personnel

Direct Care Staff (14)

Substitute Direct Care Staff

Fringe

2. Operating

Phones and Communications

Office Supplies

3. Administration

Project Director (25%)

Controller (10%)

Clerk Typist (10%)

Fringe

DDPC Start-Up: $79,819.

This is a two-year grant awarded to UCP by the Pennsylvania Developmental Disabilities Planning Council. The grant is used to support UCP project start-up costs and individual start-up costs for both UCP and TRCIL clients. The $79,819 budget included:

1. Personnel

Staff Start-Up (Staff at one cluster hired one month prior to the start of the program)

Staff Training

Fringe

2. Individual Start-Up

Rental Deposits

Phone Installation and Deposits

Furnishings/Equipment/Household Goods

TRCIL Funding. For the Supported Housing Demonstration Project, TRCIL has three major sources of funding: (1) LAMP; (2) Attendant Care; and (3) a Transition grant from the Office of Vocational Rehabilitation.

LAMP: $106,627.

Like UCP, TRCIL receives funding from LAMP for the project. TRCIL is paid at a rate of $19.50 per person per day. TRCIL pays for staff costs, administrative costs, and individual start-up costs through LAMP. TRCIL's LAMP budget of $106,627 includes the following categories:

1. Personnel

Counselors (3)

Counselor Aide (1)

Fringe

2. Administrative Personnel

Project Director (92%)

Secretary

Fringe

3. Administrative Costs

Office Rent and Utilities

Office Phone

4. Operating

Staff Travel

5. Individual Start-Up

Medical/Adaptive Equipment

Life-Call/Life-Line

Attendant Care: $143,916.

Through Attendant Care Program funds from the Department of Public Welfare, TRCIL reimburses clients for attendant care (@ $5.00 per hour) and pays for administrative personnel and operating costs. Initially, TRCIL was reimbursed for attendant care costs and experienced cash flow problems. Attendant care funds are now allocated on a prospective payment basis. The budget of $143,916 includes the following categories:

1. Attendants
2. Administrative Personnel

Personnel

Fringe

3. Operating

Office Utilities

Staff Travel

Other

Transition Grant (OVR): $20,000.

TRCIL has a Transition grant from the Office of Vocational Rehabilitation, Department of Labor and Industry for the Supported Housing Demonstration Project. This $20,000 grant includes the following categories:

1. Administrative Personnel

Personnel

Fringe

Title VII, Center for Independent Living: ($25,421)

TRCIL has a $25,421 independent living center grant from the Office of Vocational Rehabilitation earmarked for the project.

Department of Public Welfare: ($20,000, first year only).

TRCIL received a $20,000 grant from the Department of Public Welfare to help pay the costs of furniture for people supported by TRCIL.

In addition to these funding sources that directly support the Supported Housing Demonstration Project, TRCIL's two independent living center grants (Title VII, Center for Independent Living, Part A: $13,500; Title VII, Center for Independent Living, Part B: $54,000) from the Office of Vocational Rehabilitation support general administrative expenses. Since current funding sources do not support the full costs, especially administrative expenses, of the Supported Housing Demonstration Project, these grants enable TRCIL to participate in the project.

Additional Project Funding Obtained by UCP and TRCIL. In addition to grants and contracts awarded to the agencies, UCP and TRCIL have obtained a number of additional grants and loans to support individual start-up costs to enable people supported through the project to live in the community. These grants and loans have been used to make home modifications, obtain equipment, fund security and phone deposits, and pay for rent until people start receiving their income. The grants and loans include the following:

Allegheny County IMPAC Program (UCP): $1,500 Per Apartment.

The IMPAC program paid for up to $1,500 per apartment for architectural renovations at UCP's cluster apartments to make them accessible to people in wheelchairs.

Handicapped Challenge (TRCIL): $5,000.

This was a grant used to purchase household goods and to make security deposits for people served by TRCIL in 1985-86.

Westinghouse Foundation (TRCIL): $5,000.

Like the Handicapped Challenge grant, this grant pays for household goods and security deposits for people served by TRCIL. This grant covers the 1986-87 year.

Forbes Fund of the Pittsburgh Foundation: $360 Interest Free Loans to Individuals.

These loans were given to individuals served by UCP and TRCIL to enable them to pay their rent while they were waiting to receive their first Social Security of Supplemental Security Income checks.

UCP Fund-raising.

Through fund-raising, UCP purchased a van for both of the clusters. The approximate depreciation cost on both is $4,551 per year.

Office of Vocational Rehabilitation: $50,000 Per Year.

These funds are used to pay for the costs of adaptive equipment (e.g., wheelchairs, communication devices) for people served through the project.

Individual Income, Subsidies, Supplements and Benefits. In addition to grants, contracts, and other sources of funding obtained and administered by UCP and TRCIL, individuals served through the Supported Housing Demonstration Project are eligible for a variety of income maintenance programs, entitlements, supplements, and subsidies. These sources, which come directly to the individual rather than an agency, support many of the costs of living in the community. The major sources include: (1) Income Maintenance and Subsidies (SSI, SS, Domiciliary Care Supplement); (2) Housing Subsidies (Section 202 and Section 8); (3) Medical Benefits (Medical Assistance, Medicare); and (4) Food Stamps.

Income Maintenance and Supplements.

People supported through the project are eligible for Social Security (SS) and/or Supplemental Security Income (SSI). Most UCP clients also qualify for a Domiciliary Care supplement, since the UCP clusters meet state regulations for certification as a Dom Care facility. People are eligible for Dom Care if their income is under $507.30 per month and resources are under $1,800. For people who receive SS and who are eligible for SSI, the combined SSI benefits and Dom Care supplements bring their income to $507.30 per month. For people who receive only SSI, SSI benefits and Dom Care Supplements bring their income to $487.30. These sources of income pay for people's basic living expenses, including housing (although most people also receive housing subsidies, food, clothing, and personal expenses).

According to one TRCIL staff member, people served through that agency receive $372.40 in SSI benefits per month; two people also receive Social Security benefits and one person receives a modest endowment income (the income of these latter two are $600 and $650 respectively). Thus, the average income for people supported by TRCIL is $403.98. For people served through UCP, income ranges from $487.30 to $604. Sources include SS, SSI, and the Dom Care Subsidy. TABLE I summarizes the income levels of people served at the UCP cluster Apartments.

Housing Subsidies.

Most of the people served through the project are eligible for housing subsidies through federal Housing and Urban Development funds administered by local housing authorities, although the project has experienced difficulties and delays in

TABLE I

UNITED CEREBRAL PALSY
SUPPORTED HOUSING DEMONSTRATION PROJECT

INDIVIDUAL INCOME LEVELS

Versailles Castle	Social Security	Supplemental Security Income	SSI/ Domiciliary Care Supplement	Total Income
1.	$372.00	----------$135.30----------		$507.3
2.	$404.00	----------$103.30----------		$507.3
3.		$372.30	$115.00	$487.3
4.	$217.00	----------$290.30----------		$507.3
5.	$604.00			$604.0
6.	$217.00	----------$290.30----------		$507.3
7.		$372.30	$115.00	$487.3
Lindenbrooke				
1.	$453.00	----------$ 54.30----------		$507.3
2.	$423.00	----------$ 84.30----------		$507.3
3.	$480.00	----------$ 27.30----------		$507.3
4.		$372.30	$115.00	$487.3
5.		$372.30	$115.00	$487.3
6.	$286.00	----------$221.30----------		$507.3
7.		$372.30	$115.00	$487.
8.		$372.30	$115.00	$487.

obtaining subsidies. Most of the people served by TRCIL are living at facilities constructed through the Section 202 loan program and also receive Section 8 subsidies. The people served by UCP receive Section 8 subsidies. Under Section 8, subsidies are available to cover the costs of rent and utilities that exceed 30% of the person's income (although the total rent and utilities cannot exceed a fixed maximum). For seven people who qualify for Section 8 subsidies at UCP's Versailles Castle cluster, subsidies range from $27.00 to $80.00 per month, with an average of $49.14. Section 8 subsidies for the Lindenbrooke cluster range from $55.00 to $116.00 per month, with an average of $69.38. The average for both Versailles Castle and Lindenbrooke is $59.93 per month.

Medical Benefits.

People supported through the Supported Housing Demonstration Project are eligible for Medical Assistance and/or Medicare and private health insurance. These programs cover the costs of medical and health-related services, including physician services, therapy, pharmacy costs, and similar services.

Food Stamps.

Most of the people are also eligible for Food Stamps, although at a minimal amount. According to a UCP administrator, UCP clients receive approximately $10 per month worth of Food Stamps.

Funding for Support Services. While the funding sources listed above support the basic costs of the Supported Housing Demonstration Project, several additional sources underwrite the costs of support services. These include: (1) LAMP Assessment and Case Management;

(2) Day/Vocational Programs; (3) Transportation; and (4) Special Project Funding.

LAMP Assessment and Case Management.

Additional LAMP costs for the project include assessment and case management. The LAMP assessment is calculated at $185 for each person served through the project. LAMP provides case management to each person supported by UCP and TRCIL through the project, although both agencies also provide their own case management services to people. For UCP clients, LAMP case managers make monthly to quarterly visits. LAMP case management costs are calculated at $110.36 per person per month.

Day/Vocational Programs.

Each person served by UCP participates in a full-time day or vocational program, while none of the people served by TRCIL currently do. Most of the people served by UCP participate in UCP's Independent Living Rehabilitation program; five of these people attended the program while they were living at Kane. While initial plans called for the Office of Vocational Rehabilitation to pay for the costs of day and/or vocational programs, the Human Service Development Fund (HSDF) is currently used to pay for these costs. UCP has also received a Supported Work grant from the DDPC that will be used to support eight people served by the project in community work placements.

Transportation.

Many people served by the project use the subsidized ACCESS door-to-door transportation service, although they pay part of the costs of this service through their own funds. As noted above, UCP also purchased a van for each of the clusters, since

people could not afford to pay for ACCESS on a regular basis and ACCESS is viewed as unreliable and inconvenient. People contribute towards the maintenance of the van.

Special Project Funding.

UCP received a modest grant from DDPC for a demonstration project to increase community participation among people served at the Versailles Castle and Lindenbrooke clusters.

FIGURE III illustrates the relationship of the costs of the Supported Housing Demonstration Project to major project funding sources.

An Analysis of Costs and Funding

An analysis of the costs and funding of the Supported Housing Demonstration Project reveals a number of important policy issues. First of all, no stable funding mechanism exists to support the operating or start-up costs of the project. The project is supported through a patchwork quilt of one-time grants, purchase of service arrangements and contracts, individual sources of income, entitlement programs, and miscellaneous sources.

Since stable funding does not exist to support people with physical disabilities in the community, there are disparities in the funding available to support people served by UCP and TRCIL respectively. For example, while UCP and TRCIL clients may have comparable living expenses, TRCIL clients have lower incomes, since they do not receive the Dom Care supplement. Similarly, UCP and TRCIL have accessed different sources of funding to serve people. TRCIL's Transition grant pays for general operating expenses; UCP's clients are able to participate in day programs because of HSDF funding that is not available to TRCIL clients.

FIGURE III

SUPPORTED HOUSING DEMONSTRATION PROJECT
RELATIONSHIP OF COSTS TO FUNDING SOURCES

Funding Sources	Agency Start-up		Costs Individual Start-up		Program Support Start-up		Agency Operating Costs		Individual Expenses		Ongoing Program Support	
	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL
LAMP-UCP and TRCIL Contracts							X	X		X		
LAMP-Assessment and Case Management					X	X					X	X
HSDF-UCP Contracts							X					
HSDF Day Program											X	
Attendant Care Program							X	X				
DDPC Start-up Grant	X		X	X								
DDPC Supported Work Grant											X	X
DDPC Community Participation Grant											X	
OVR Transition Grant								X				

FIGURE III(Continued)

SUPPORTED HOUSING DEMONSTRATION PROJECT
RELATIONSHIP OF COSTS TO FUNDING SOURCES

Funding Sources	Agency Start-up		Individual Start-up		Program Support Start-up		Agency Operating Costs		Individual Expenses		Ongoing Program Support	
	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL
OVR Adoptive Equipment									X	X		
OVR Independent Living Center								X				
UCP Fund-raising (Vans)									X			
Allegheny County IMPAC Program			X									
Handicapped Challenge				X								
Westinghouse				X								
Forbes Fund of the Pittsburgh Foundation			X	X								
Social Security and Supplemental Security Income									X	X		
DOM CARE									X			
Section 8/Section 202									X	X		

FIGURE III (Continued)

SUPPORTED HOUSING DEMONSTRATION PROJECT
RELATIONSHIP OF COSTS OF FUNDING SOURCES

Funding Sources	Agency Start-up		Costs Individual Start-up		Program Support Start-up		Agency Operating Costs		Individual Expenses		Ongoing Program Support	
	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL	UCP	TRCIL
Medical Assistance/ Medicare/Private Insurance									X	X		
ACCESS Subsidized Transportation									X	X		
Food Stamps									X	X		
DPW Start-up Grant				X								
Center for Independent Living, Title VII Grant								X				

Start-up costs associated with the project ranging from staff preparation and training and field office set-up to individual security deposits, furniture, equipment purchases, and home renovations have been funded by one-time grants and loans. Without grants and loans from DDPC, the IMPAC program, the Pittsburgh Foundation, Handicapped Challenge, and Westinghouse, none of which can be depended upon for additional support, people would never have been able to move from Kane and other institutions into the community.

Second, the Supported Housing Demonstration Project is funded primarily by state sources and indirectly federal sources. Major funding for the project has come from state agencies (Department of Aging funds funneled through LAMP; OVR grants; DDPC grants; Department of Public Welfare HSDF funds and Attendant Care Program funds) and federal/state entitlement programs (SS, SSI, Medical Assistance). In contrast to the Kane regional centers, which receive over 30% of their funding from Allegheny county, county funding for the Supported Housing Demonstration Project is minimal.

Third, people served through the project do not appear to have sufficient incomes. While none of the people appear to be living in impoverished circumstances, their incomes limit their opportunities in the community. According to UCP staff, without the Dom Care Supplement, clients do not have enough money to afford basic amenities most people take for granted. For both people served by UCP and TRCIL, transportation, laundry, and other living expenses seem to take up an inordinate amount of their incomes. Further, since TRCIL clients are dependent on Section 202/Section 8 subsidies and UCP clients are dependent on Section 8 subsidies and Dom Care

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supplements, their housing options are severely circumscribed because much of the available housing in the community cannot qualify under these programs.

Finally, funding for the project is inadequate to meet actual project costs. While the project seems adequately funded in terms of the number of sources of funding, this is not the case. Perhaps one of the reasons why so many funding sources have been tapped for the project is that the major funding sources fail to cover the costs of supporting people in the community.

UCP and TRCIL have different budgeting procedures and funding configurations. UCP is funded through a range of program grants and contracts and purchase of service arrangements in addition to United Way and telethon funds and other contributions. UCP's agency budget is broken down into cost centers corresponding to specific projects and activities. TRCIL is funded through project grants, contracts, and purchase of service arrangements. Unlike UCP, TRCIL receives a very small amount of funds not related to specific projects. For this reason, all TRCIL expenditures are charged to specific accounts corresponding to funding sources. Also unlike UCP, TRCIL does not break down its budget according to cost centers.

Neither UCP nor TRCIL receive adequate funding for the Supported Housing Demonstration Project to cover their costs. For example, LAMP, the Attendant Care Program, and other project budgets do not include sufficient funds to cover general administrative costs. For TRCIL, the two independent living center grants make up the difference between project funding and project costs. For UCP, however, the Supported Housing Demonstration Project is operated at a deficit.

A review of UCP's costs and budgets indicates four major areas in which it incurs a deficit for the Supported Housing Demonstration Project:

1. General Administrative Costs. Funding for the project covers minimal administrative costs associated with operating a program. With the exception of personnel and fringe for a controller (6% charged to LAMP and 10% charged to Attendant Care), no general administrative costs are included in project budgets. For example, UCP does not receive funding for administrative office space, equipment maintenance, phone installation, and administrative salaries and fringe.

2. Project Director Salary and Fringe. At the present time, only 50% of the salary of the Project Director of the Supported Housing Demonstration Project is charged to project budgets (25% to LAMP and 25% to the Attendant Care Program). Since the Project Director is assigned full-time to the project, this is a major cost that UCP must pay for from its general operating budget.

3. Operating Expenses. Current project budgets are inadequate to fund the full costs of project operating expenses such as staff travel, instructional supplies, and miscellaneous costs.

4. Individual Expenses. Since people supported by UCP do not have adequate personal incomes and since delays are sometimes encountered in receiving subsidies and supplements, UCP subsidizes many of people's individual expenses through its general operating budget. For example, UCP has paid for ambulance costs for one individual and has helped people pay rent and utilities while they were waiting to receive Section 8

subsidies.

Complicating UCP's funding picture are two additional factors. One is that LAMP and HSDF funds are only received for days people actually spend in their apartments. When people have short-term hospital stays, UCP cannot charge for services even though UCP costs do not decrease (e.g., the same number of staff is still required). A second complicating factor is that apart from the DDPC grant that funded partial agency start-up costs at one of the clusters, UCP has no way to fund assessment costs, staff planning and preparation, staff training, and other costs related to starting up a program.

During 1986 (calendar year), UCP ran a deficit of $23,627 for the Supported Housing Demonstration Project, excluding general administrative costs, loans to clients, and van depreciation. TABLE II, prepared by UCP and based on its cost center accounting method, lists its deficit for each of the major project funding sources. In the TABLE, "Amounts Received" refers to actual funds received from each funding source (note that this does not correspond to the budget since the project was not fully operational during the entire calendar year); "Amounts Expended" refer to actual project costs; and "Deficit" refers to the difference between these two figures.

Funding for the Supported Housing Demonstration Project stands in sharp contrast to funding for services for people with mental retardation and mental health problems in Allegheny County and Pennsylvania. UCP holds contracts with the Allegheny County Mental Health/Mental Retardation Program for the operation of CLA (Community Living Arrangement) programs for people with mental retardation, which are similar to the Supported Housing Demonstration Project clusters. A comparison of funding for CLA programs for people with

TABLE II

UNITED CEREBRAL PALSY
SUPPORTED HOUSING DEMONSTRATION
PROJECT DEFICIT

1986

Funding Source	Amount Received	Amount Expended	Total Deficit
HSDF	$ 13,624	$ 16,566	$ 2,942
LAMP	$ 53,287	$ 69,967	$16,680
Attendant Care Program	$140,477	$142,500	$ 2,023
DDPC (Start-up: 1986 Funds Only)	$ 27,959	$ 29,941	$ 1,982
TOTAL DEFICIT			$23,627

mental retardation with the Supported Housing Demonstration Project underscores the inadequacy of funding for community services for people with severe physical disabilities.

Whereas funding for the Supported Housing Demonstration Project has been pieced together through a host of purchase of service agreements, contracts, grants, and loans, funding for UCP's CLAs comes from single contracts with the Allegheny County Mental Health/Mental Retardation Program. Like the Supported Housing project, funding for the CLA program comes from multiple sources, including federal, state, and county funds. Of the 40 people served through the CLA program, nine are funded through a Title XIX Medicaid waiver. In contrast to the Supported Housing Demonstration Project, however, the multiple sources of funding for the CLA program are channeled through single contracts with Allegheny County.

Also in contrast to the Supported Housing Demonstration Project, UCP's contracts with Allegheny County for CLAs fund the actual costs of supporting people in the community. As in the case of the Supported Housing project, people living in the CLAs pay their own rent, utilities, food, clothing and personal expenses through personal income (primarily SSI) supplemented by Section 8 subsidies and are covered by Medical Assistance for medical and health-related services. All other program costs are covered in the contracts with Allegheny County. The contracts for CLA programs include the following budget categories: Wages and Salaries; Employee Benefits; Staff Development ($1,118 in one budget and $2,875 in another); Purchased Personnel Services; Other Personnel Services; Rent (staff office); Utilities (staff office); Insurance; Housekeeping;

Communications; Office Supplies; Food and Clothing (minimal amounts); Staff Travel ($1,000 in one budget and $2,400 in another); Client Transportation (minimal amounts); Other Operating Expenses; Administrative Costs ($18,101 in one budget and $32,360 in another); Other Equipment and Furnishings; Motor Vehicles ($10,514 in one budget and $14,365 in another). In addition, the contracts with the Allegheny County Mental Health/Mental Retardation Program will cover start-up costs and will subsidize clients' rent and utilities if necessary.

FIGURE IV compares funding for the Supported Housing Demonstration Project with funding for UCP's CLA programs. A final note that should be added in comparing funding for the Supported Housing Project is that the CLA contracts provide for a higher level of funding and richer staffing in order to serve people with more severe disabilities and challenging needs.

In short, funding for the Supported Housing Demonstration Project is complex, unstable, and inadequate to meet the actual costs of supporting people with severe physical disabilities in the community. This is often the case with demonstration projects. In order to support additional people with severe physical disabilities in the community, a more stable, secure, and realistic funding mechanism will be required.

A Comparison of the Costs of the Project with Kane Regional Centers

The issue of the cost of services is a controversial one in the field of disabilities. Some policymakers, on the one hand, believe that cost factors should be used to guide public policy; for example, the issue of institutionalization versus community living. Other policymakers, professionals, and advocates, on the other hand, make a

FIGURE IV
A COMPARISON OF FUNDING FOR UCP'S
SUPPORTED HOUSING DEMONSTRATION PROJECT WITH
UCP'S CLA PROGRAM

	SUPPORTED HOUSING DEMONSTRATION PROJECT	CLA PROGRAM
Funding Sources	Multiple	Multiple, including Title XIX Medicaid Waiver
Funding Mechanism	None-Funding through a diverse range of public and private grants, contracts and purchase of service agreements	Single contracts with Allegheny County Mental Health/Mental Retardation Program
Funding of Costs		
Start-Up Costs	Private grants and loans and DDPC grants; Start-up costs inadequately funding	Start-up costs fully funded through contracts
Individual Living Expenses (Rent, Utilities, Food, Clothing, Personal Expenses)	Personal Income, Section 8 Subsides, DOM care; Funding inadequate or minimally adequate	Personal Income; Section 8 Subsidies; contracts will supplement if necessary
Medical and Health Costs	Medical Assistance	Medical Assistance
Personnel Costs	Public grants, contracts, and purchase of service agreement; total costs not funded	Fully funded through single contracts
Equipment and Fixed assets	Private grants; total costs not funded	Fully funded through single contracts
Operating Costs	Public and private grants, contracts, purchase of service agreements; UCP runs a deficit	Single contracts; operating costs fully funded
Administrative Costs	Minimally funded	Fully funded through single contracts

persuasive case that dollar figures cannot be placed on quality of life, civil rights, and human dignity. The position taken here is that while cost factors should not be used to set public policy directions, policy decisions should be informed by an understanding of the economic as well as human and social implications of different alternatives.

It is difficult to analyze the costs of any social program. Cost comparisons of institutions versus community programs are especially complex. In the first place, all programs have hidden costs; that is, costs that do not appear in program budgets. For example, institutions may not include state or local governmental administrative costs in their budgets; community programs may not take into account the costs of generic community services. In the second place, in order to be valid, a cost comparison must be based on comparable populations; that is, costs must be compared for people with the same level of needs. A common failing of cost studies of institutions versus community services is that they have compared the costs of serving people with severe disabilities with those with mild disabilities. In the third place, cost studies must be based on the costs of comparable levels of service. It is misleading to compare the cost of an understaffed program with the cost of a richly staffed one. In the final place, while economic factors or costs lend themselves to quantification, many other critical factors, such as quality of life and human dignity, defy measurement. For many public policy issues, it is impossible to conduct a valid cost-benefit analysis.

In this review, only a general comparison of the costs of the Supported Housing Demonstration Project can be made and any findings

or conclusions must be viewed as tentative. No claim is made that this review addresses the limitations of cost studies described above. In additional to these limitations, insufficient data were available on all costs for this review.

The question guiding this review is a simple one: Is it reasonable to conclude that the costs of the Supported Housing Demonstration Project are no greater than the costs of the Kane Regional Centers?

Costs of the Supported Housing Demonstration Project

Since the Supported Housing Demonstration Project is funded by such a broad range of public and private sources and since some costs must be estimated, it is difficult to calculate the total costs of the project. This section provides estimates of the costs of supporting people to live in the community through the project.

In calculating the costs of the project, the following were not included:

1. Since this review focuses on community living, or residential services, the costs of day programs and UCP's supported work program are excluded from the analysis. The Kane centers' budget may not include all of these costs; five of the eight people at one of UCP's clusters attended UCP's day program while living at the Kane centers. In addition, no day program/vocational costs are currently incurred for people supported by TRCIL.
2. The public costs of subsidizing the ACCESS transportation service are not included. While this may be a cost associated with the project, many people living at the Kane centers also use this service. UCP also purchased a van for each of the clusters. In addition to the public subsidy for ACCESS,

individuals pay per ride out of their own incomes.

3. The costs of UCP's community participation grant from DDPC are not calculated. This is a one-time demonstration grant, which is separate from the operation of the Supported Housing Demonstration Project.

4. The grant from the Office of Vocational Rehabilitation for adaptive equipment is not figured in the calculations. While this grant was used to purchase adaptive equipment for people served through the project, the costs of adaptive equipment are not specific to living in the community. Presumably, people living at the Kane centers also require adaptive equipment that is not calculated in Kane's budget.

5. The LAMP one-time assessment cost of $185 per person is not included (although case management costs are). LAMP provides assessments for both community living and nursing home placement.

6. The interest-free loan of $360 per person from the Forbes Fund of the Pittsburgh Foundation is excluded from the cost analysis.

It should also be noted that all calculations are based on the budgets for the Supported Housing Demonstration, rather than the amounts actually received from funding sources, and on the costs of serving 32 people through the project, 16 through UCP and 16 through TRCIL.

United Cerebral Palsy. TABLE III contains a breakdown of UCP's annual total and per person costs for the project for 1986-87. TABLE III lists four broad categories of cost:

1. UCP Operating Costs. These include LAMP, HSDF, and Attendant Care Program funds; Personal Income (SS, SSI, Dom Care);

TABLE III

SUPPORTED HOUSING DEMONSTRATION PROJECT

ESTIMATED COSTS: UCP

1986-87

Costs	Cumulative Total	Cumulative Per Person Per Year Cost	Per Diem
Operating LAMP HADF Attendant Care Program Personal Income (SS, SSI, DOM Care) Section 8 Subsides*	$427,569	$26,724	$73.21
Operating and LAMP Case Management	$448,758	$28,048	$76.84
Operating, LAMP Case Management and Depreciation* (Vans; Equipment and Furnishings - DDPC; IMPAC)	$467,760	$29,236	$80.10
First Year Only: Operating, LAMP Case Management Depreciation, and DDPC Agency Start-up (First Year Only)	$472,579	$29,537	$80.92

*Estimates

estimated Section 8 subsidies (based on an average Section 8 subsidy of $59.93 for both Versailles Castle and Lindenbrooke apartments; and estimated food stamp costs.

2. LAMP Case Management. This is LAMP's cost for case management services.

3. Depreciation Costs. These include UCP's approximate depreciation expenses for the two vans and estimated costs of the DDPC furniture and equipment grant and the IMPAC grant. For the purposes of estimated the annual costs of the DDPC grant and IMPAC grant, the total figures are evenly depreciated over a five-year period.

4. UCP DDPC Start-Up Grant. Of the $79,819 DDPC start-up grant, $4,819 was used by UCP for agency start-up expenses. This is a one-time cost of establishing the program and should be figured into costs for the first year of the project only.

As indicated in this TABLE, the estimated annual cost of UCP's project is $29,236 per person per year, or a per diem of $80.10. Total estimated project costs are $467,760. For the first year only, estimated costs are slightly higher: $29,537 per person per year; $80.92 per diem; $472,579 total costs.

If UCP's deficit described in the previous section were included in these cost calculations, the estimated total cost of the project would rise to $491,387, the person per year cost to $30,712, and the per diem to $84.14. For the first year only, these figures would be $496,198, $31,013, and $84.96.

Three Rivers Center for Independent Living. TABLE IV contains a breakdown of the estimated total and per person TRCIL annual costs for the project for 1986-87. This TABLE contains three categories:

TABLE IV

SUPPORTED HOUSING DEMONSTRATION PROJECT

ESTIMATED COSTS: TRCIL

1986-87

Costs	Cumulative Total	Cumulative Per Person Per Year Cost	Per Diem
Operating LAMP ATTENDANT CARE PROGRAM TITLE VII TRANSITION GRANT PERSONAL INCOME (SSI, SS, OTHER)* SECTION 8/ SECTION 202* FOOD STAMPS*	$386,956	$24,185	$66.26
Operating and LAMP Case Management	$408,145	$25,509	$69.89
Operating, LAMP Case Management and Depreciation* (Furniture and Equipment-DDPC Handicapped Challenge, Westinghouse, DPW Start-up Grant)	$421,645	$26,353	$72.20

1. TRCIL Operating Costs. These include LAMP, Attendant Care, one of the Title VII grants, and Transition grant funds; estimated personal income; estimated food stamps costs; and estimated Section 202/Section 8 subsidies (these subsidies are estimated based on UCP's Section 8 subsidies).

2. LAMP Case Management. This is the same figure as LAMP's case management costs for UCP clients.

3. Depreciation Costs. These include the costs of DDPC's furniture and equipment grant, the DPW start-up grant, and the Handicapped Challenge and Westinghouse grants. As in the case of UCP's costs, these costs are depreciated evenly over a five year period.

As indicated in TABLE IV, TRCIL estimated annual cost per person per year for the project is $26,353 or a per diem of $72.20. Total estimated project costs are $421,645.

These figures do not include TRCIL independent living center grants that support some of the project's administrative costs.

As TABLES III and IV indicate, estimated costs for UCP are higher than those for TRCIL's. While this may partially reflect less reliable data on TRCIL, the major factor accounting for the cost differences is probably the higher level of staff support required by people served by UCP.

Costs of the Kane Regional Centers

The Kane Regional Centers are funded through federal, state, third-party, and county sources. Major funding for the Kane centers comes from the Pennsylvania Medical Assistance Program and Allegheny County funds.

The 1987 operating budget for the Kane Regional Centers is

$57,615,706. This budget includes $36,112,098 in Personnel and Fringe Benefits and $11,985,273 in Debt Service. Of the $57,615,706 budget for the Kane centers, Allegheny County's share is $18,069,506, or over 31% of the budget, with $39,546,200 coming from other revenues as follows:

*Medical Assistance pharmacy charges (approximately $1 million).

*Medicare Part A and B (approximately $1 million).

*Medical Assistance, patient funds, third-party payments (approximately $37 million). Under the Medical Assistance program, the Kane centers are allowed $78.30 per patient day for Skilled Nursing Facility (SNF) care and $61.48 per patient day for Intermediate Care Facility (ICF) care. In addition, the Kane centers are allowed amounts ranging from $6.65 to $7.54 per patient day for depreciation and interest under the Medical Assistance program.

CHART I illustrates Allegheny County's share of the budget of the Kane Centers.

The budget for Kane Regional Centers does not include a range of other costs associated with services for people living at Kane. The following costs are not included in the budget and, as in the case of UCP and TRCIL, are excluded from this analysis:

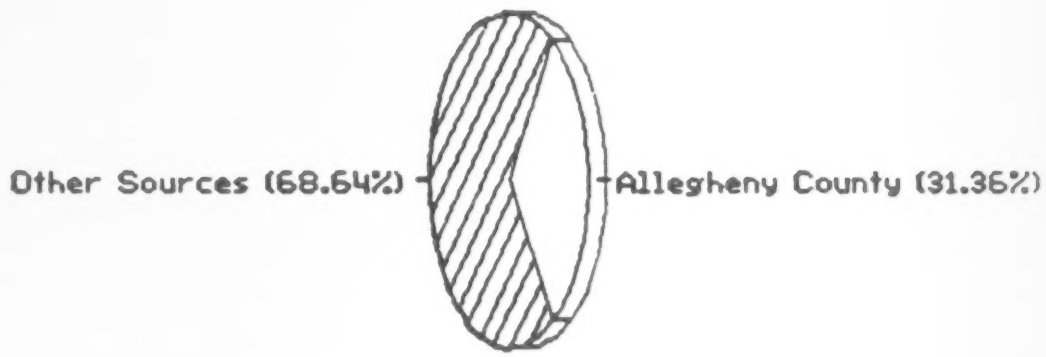
1. Physician services, physical therapy, speech therapy, and the majority of medical and surgical supplies are billed to Medical Assistance independently.

2. Personal funds (e.g., SSI) which under the Medical Assistance Program each person is allowed $25 per month for personal use.

3. Public costs of subsidizing the ACCESS transportation service. People living at the Kane centers may use ACCESS for

CHART I

KANE REGIONAL CENTERS BUDGET
$57,615,706.00



Other sources of revenue include Medical Assistance, Medicare Part A & B, patient Funds and other sources.

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personal trips.

4. LAMP assessment costs.

5. Costs of day programs or vocational services offered by other agencies. As noted previously, five of the eight clients at one of UCP's cluster apartments attended day program at UCP while living at the Kane centers. It is unknown how many people currently living at the Kane centers are involved in programs operated by other agencies.

As in the case of any large institution, the average cost of serving people at the Kane centers may be misleading. Costs vary dramatically from individual to individual, with some people costing much higher than the average and others costing much lower. At Kane, the costs of SNF care run higher than the costs of ICF care.

It is as difficult to estimate the costs of serving any particular individual at the Kane centers as it is to estimate the costs of serving individuals through the Supported Housing Demonstration Project. All cost figures are approximated and should be interpreted as general estimates.

One way to calculate the costs of serving an individual at the Kane Regional Centers is to divide the total operating budget by the capacity of the four centers, which is 360 beds (240 ICF beds and 120 SNF beds) at each of the four centers (note that the capacity may be different than the census of the centers). Using this calculation, the average cost at the Kane Regional Centers is $40,011 per person per year or a per diem of $109.62.

This figure may over-estimate the costs of serving nonelderly severely physically disabled people, those who are supported through the Supported Housing Demonstration Project, at the Kane regional

centers. The Kane centers offer both SNF and ICF care, with the costs of ICF care being lower than SNF care. People served through the Supported Housing Project generally received an ICF level of care at the Kane centers and thus the costs of their care may have been lower than a general average figure. However, it could also be argued that younger, severely disabled people receive more active treatment and services and, hence, cost more to serve.

While per diem figures for SNF and ICF levels of care based on the total Kane centers' operating budget are not available, the Kane centers do have per person per day reimbursement rates for SNF and ICF care under the Medical Assistance program of $78.30 and $61.48 respectively. Setting the mid-point of these two rates at $69.89, the SNF rate is 112% of the mid-point and the ICF rate is 88% of the mid-point. Applying these percentages to the average per person cost at the Kane Regional Centers, Kane costs range from $44,812 for SNF care, a per diem of $122.77, to $35,210 for ICF care, a per diem of $96.47. Using a different method of calculation weighted according to the ratio of SNF to ICF certified beds (1:2), the SNF rate is 117% of the average cost at the Kane centers and the ICF rate is 92% of that cost. Applying this figure to the average cost at Kane, Kane costs range from $46,815 for SNF care, a per diem of $128.26, to $36,810 for ICF care, a per diem of $100.85. Conservative estimates of the costs of the Kane Regional Centers for nonelderly severely physically disabled people range from $35,210 to $36,810 per person per year or a per diem of from $96.47 to $100.85.

TABLE V summarizes cost information of the Kane Regional Centers. Since the estimated costs of UCP's program are $80.10 and TRCIL's program are $72.20, it is reasonable to conclude that the costs of

TABLE V

KANE REGIONAL CENTERS

BUDGET AND ESTIMATED COSTS

1987

Operating Budget:	$57,615,706
Revenues (Medical Assistance, Medicare Part A and B, Other Third - Party Revenues):	$39,546,200
Net Allegheny County Share:	$18,069,506
Estimated Average Cost(1,440 people)	
Per Person Per Year:	$40,011
Per Diem:	$109.62
Estimated Average Costs for Nonelderly, Severely Physically Disabled People	
Per Person Per Year:	$35,210-$36,810
Per Diem:	$96.47- $100.85

the Supported Housing Demonstration Project are significantly lower than the costs of the Kane Regional Centers. In fact, the estimated cost differential ranges from $5,974 to $10,457 per person per year or from $16.37 to $28.65 at a per diem rate. For 32 people served by the Supported Housing Demonstration Project, the total estimated cost differential ranges from $237,296 to $288,496.

TABLE VI compares the estimated costs of the Supported Housing Demonstration Project with the estimated costs of the Kane centers.

CHART II illustrates the difference in average annual costs between the Supported Housing Demonstration Project - UCP and TRCIL - and low and high estimates for nonelderly severely physically disabled people at the Kane Centers. CHART III illustrates the difference in terms of per diems.

It is important from a policy standpoint to note that the estimated costs of the Supported Housing Demonstration Project are within the range of the Medical Assistance reimbursement rates for ICF and SNF care at the Kane Regional Centers. The estimated annual per person costs of the Supported Housing Demonstration Project range from $26,353 to $29,236 (per diems of $72.20 to $80.10), while the Medical Assistance annual per person rates rates for ICF and SNF care, including operating costs and depreciation and interest, range from $24,867 (per person day rate of $68.13) to $31,332 (per person day rate of $85.84). Thus, even if the Allegheny County share of the costs Kane Regional Centers are excluded, the costs of the Supported Housing Demonstration Project are comparable to the costs paid under the Pennsylvania Medical Assistance Program.

In addition to the differences in the costs of the Supported Housing Demonstration Project and the Kane Regional Centers, it

TABLE VI

COMPARISON OF ESTIMATED COSTS OF
THE SUPPORTED HOUSING
DEMONSTRATION PROJECT AND THE KANE REGIONAL CENTERS

	Estimated Per Person Per Year	Estimated Per Diem
Supported Housing Demonstration Project		
UCP	$29,236	$80.10
TRCIL	$26,353	$72.20
Kane Regional Centers		
Average	$40,011	$109.62
Nonelderly, Severely Physically Disabled People	$35,210-$36,810	$96.47-$100.85
Cost Differential: Supported Housing Demonstration Project and Kane Regional Centers (Nonelderly, Severely Physically Disabled People)	$5,974-$10,457	$16.37-$28.65

CHART II

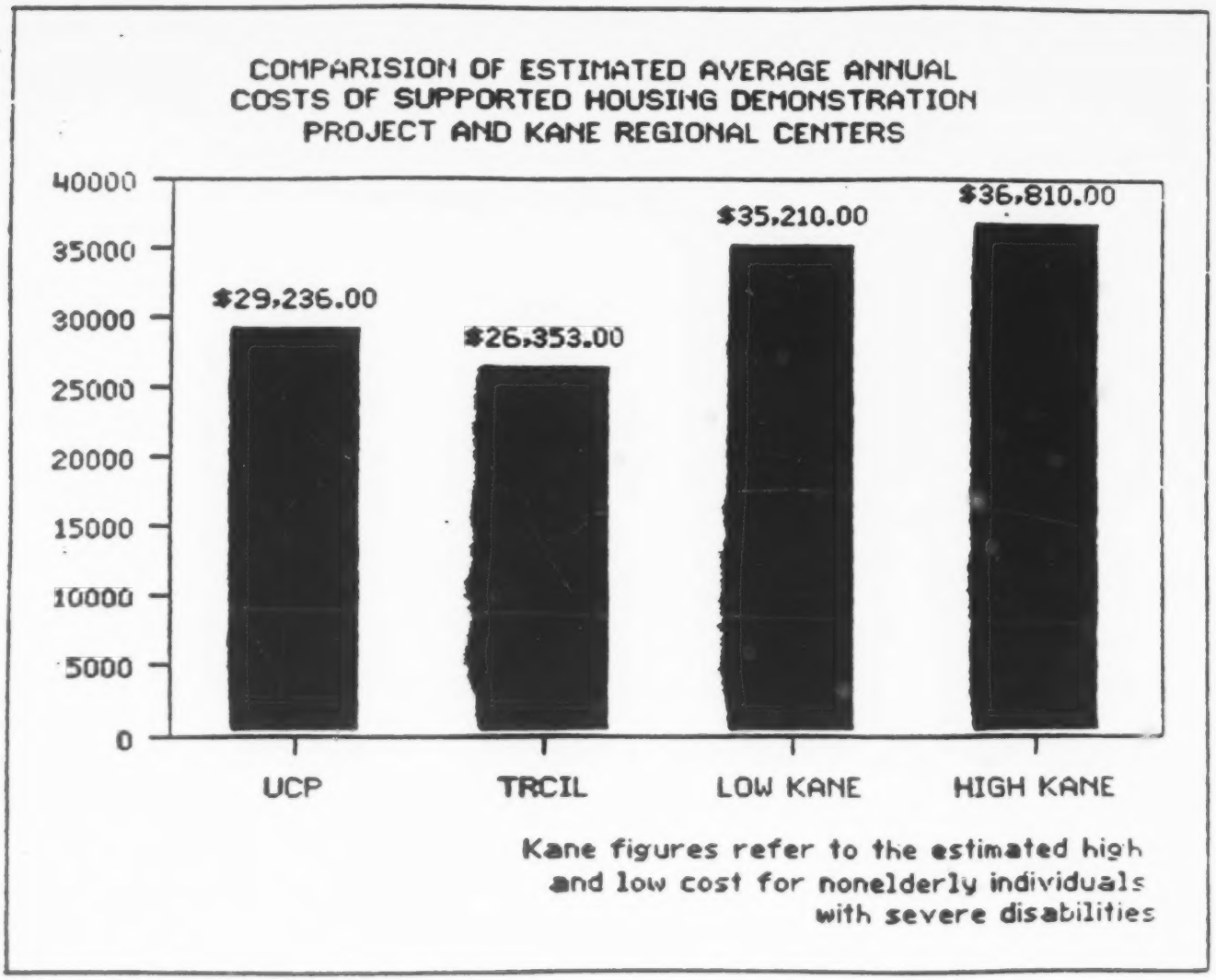
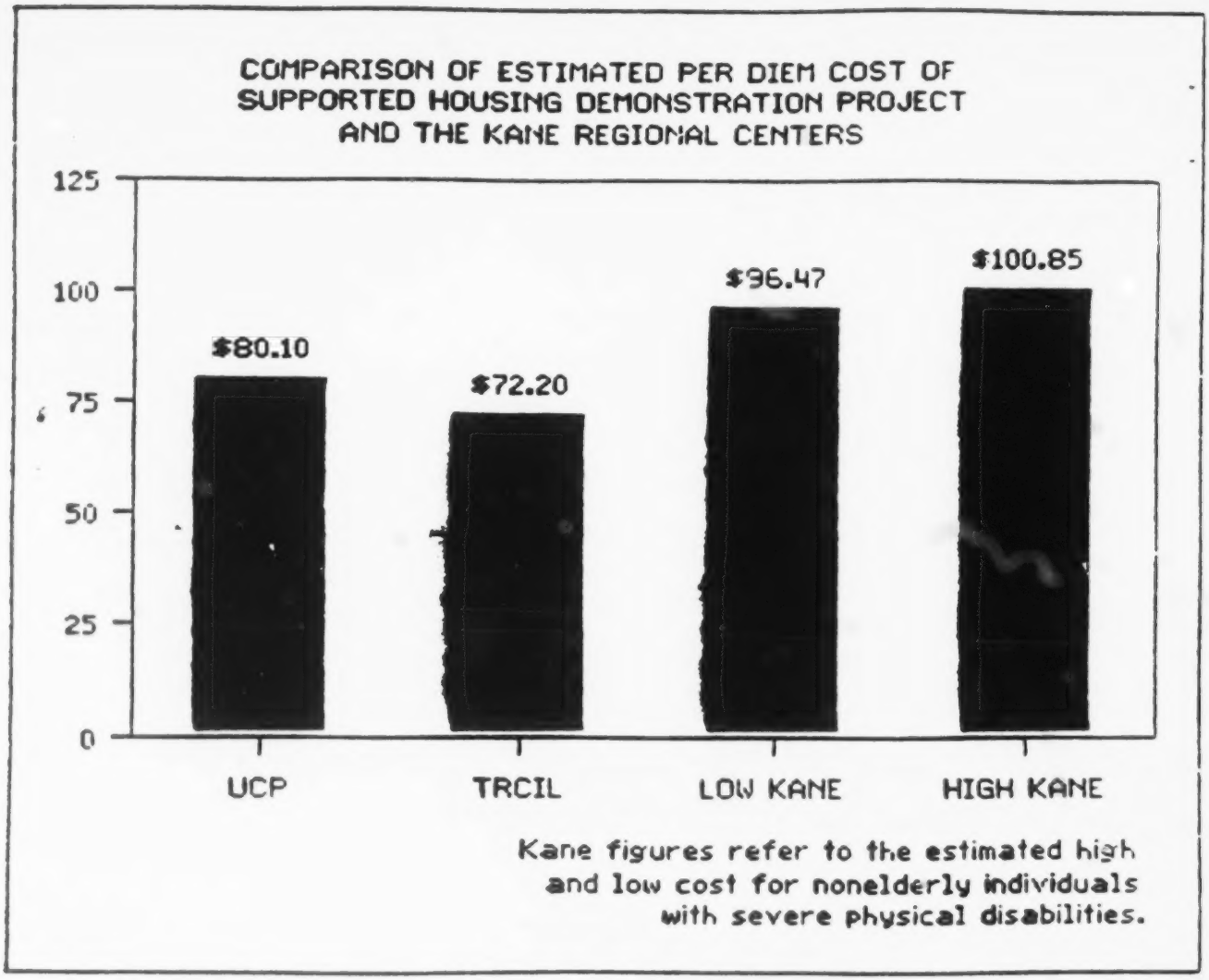

COMPARISION OF ESTIMATED AVERAGE ANNUAL COSTS OF SUPPORTED HOUSING DEMONSTRATION PROJECT AND KANE REGIONAL CENTERS
40000
35000
30000
25000
20000
15000
10000
5000
0
$29,236.00
$26,353.00
$35,210.00
$36,810.00
UCP
TRCIL
LOW KANE
HIGH KANE
Kane figures refer to the estimated high and low cost for nonelderly individuals with severe disabilities

CHART III


COMPARISON OF ESTIMATED PER DIEM COST OF
SUPPORTED HOUSING DEMONSTRATION PROJECT
AND THE KANE REGIONAL CENTERS
125
100
75
50
25
0
$80.10
$72.20
$96.47
$100.85
UCP
TRCIL
LOW KANE
HIGH KANE
Kane figures refer to the estimated high
and low cost for nonelderly individuals
with severe physical disabilities.

should be pointed out that many people associated with the project believe that the costs of supporting people in the community will decrease over time as they become more independent.

In view of the dramatic increase in quality of life experienced by people served through the Supported Housing Demonstration Project, the fact that the estimated costs of the project are significantly lower than the costs of placement at the Kane Regional Centers provides a strong justification for supporting on a policy level the direction set by the project.

POLICY IMPLICATIONS AND RECOMMENDATIONS

While the Supported Housing Demonstration Project is still in its infancy, it has important lessons to offer with regard to public policy on people with severe physical disabilities in Pennsylvania and Allegheny County. As the project develops, additional lessons will be learned. However, the experience to date strongly suggests that the direction set by the project is deserving of state and county support and resources.

As a <u>demonstration</u> project, the Supported Housing Demonstration Project has demonstrated that:

1. People with severe disabilities living in nursing homes and similar facilities can live successfully in the community.
2. People who have moved from nursing homes and similar facilities to the community experience a dramatic increase in the quality of their lives.
3. People with severe disabilities can be supported in the community at no greater cost, and, in fact, at a lower cost, than nursing homes and similar facilities.

In view of the experience with this project and similar efforts in other states, questions like "Is it a good idea?" and "Will it work?" no longer seem appropriate. Rather, it is time to ask "How can the project be strengthened" and "How can the lessons of the project be applied to benefit other people with severe physical disabilities in Pennsylvania and Allegheny County?"

Before addressing the policy implications and recommendations coming from this review, the major findings contained in this report should be reviewed.

Major Findings: Supported Housing Demonstration Project

1. UCP's operation of the project is characterized by the following strengths:

*The apartment clusters are located in typical apartment complexes in the community and, hence, afford people the opportunity to live alongside nondisabled people.

*People served through the project are involved in a range of community activities.

*People receive the necessary supports to meet their programmatic needs and insure safety.

*People rent their own apartments and selected their own furniture and furnishings.

*UCP has aggressively pursued strategies to enhance the quality of life and increase the degree of community participation of people served through the project.

2. TRCIL's operation of the project is characterized by these strengths:

*People are in control of their own lives and make their own decisions.

*People rent their own apartments and selected their own furniture and furnishings.

*People receive the basic services and supports they require to live safely and successfully in the community.

3. People supported through the project have experienced a dramatic increase in the quality of their lives.

4. People served through the project point to independence, freedom, and having their own homes as the major benefits of community living as opposed to institutionalization.

5. Over 18 public and private agencies and organizations have come together to operate, fund, and support the project.

6. No single public agency has taken a lead role in planning and coordinating services for people with severe physical disabilities.

7. The project would never have been implemented without an extraordinary commitment from UCP and TRCIL.

8. The project has experienced and continues to experience a precarious existence.

9. No stable funding exists to support the movement of people with severe physical disabilities from institutions to the community.

10. Twenty-two identifiable funding sources have been used to pay the costs of supporting people through the project.

11. No funding mechanism exists to support the start-up or operating costs of the project.

12. The project is funded primarily by state sources and indirectly federal sources.

13. People served through the project do not appear to have sufficient incomes.

14. Funding for the project is inadequate to meet actual project costs.

15. During 1986, UCP ran a deficit of $23,627 for the project.

16. The estimated cost of UCP's project is $29,236 per person per year or a per diem rate of $80.10.

17. The estimated cost of TRCIL's project is $26,353 per person per year or a per diem rate of $72.20.

18. The 1987 operating budget for the Kane Regional Centers is $57,615,706.

19. Allegheny County's share of the budget of the Kane Regional Centers is $18,069,506 or 31% of the total budget.

20. The estimated cost at the Kane Regional Centers is $40,011 per person per year or a per diem rate of $109.62.

21. The estimated costs for the Kane Regional Centers for nonelderly severely physically disabled people ranges from $35,210 to $36,810 per person per year or a per diem rate ranging from $96.47 to $100.85.

22. It is reasonable to conclude that the costs of the Supported Housing Demonstration Project are significantly lower than the costs of the Kane Regional Centers.

Recommendations

The following recommendations are based on the findings of this review of the Supported Housing Demonstration Project.

Recommendation 1. The direction set by the Supported Housing Demonstration Project should be adopted in state and county policy.

It is in the interest of the Commonwealth and the counties, and Allegheny County in particular, to support people with severe physical disabilities in the community as an alternative to

institutional placement. The findings of this review unequivocally support this direction. The movement of people with severe physical disabilities from institutions to the community yields clear benefits from either a humanitarian or economic standpoint.

In the field of mental retardation, the Commonwealth of Pennsylvania has achieved a reputation for national leadership in the movement of people from public institutions to the community. Pennsylvania, along with states like Michigan, Nebraska, and Rhode Island, stands at the forefront of the deinstitutionalization movement for people with mental retardation. With the experience gained through this deinstitutionalization as well as the Supported Housing Demonstration Project and similar initiatives, the Commonwealth has the opportunity to exercise national leadership in community integration and independent living for people with severe physical disabilities. In fact, Pennsylvania's Attendant Care Demonstration Program (now established firmly in legislation) was recently singled out as having the highest independent living orientation in the country by the World Institute on Disability.

Recommendation 2. A single state agency should take the lead role in the planning and coordination of community services for people with severe physical disabilities.

At the present time, responsibility for services for people with severe physical disabilities is divided between three major state departments: the Department of Public Welfare; the Department of Labor and Industry; and the Department of Aging. Within each of these agencies, several offices or programs may fund programs for people with severe disabilities. By contrast, services for people with mental retardation and mental health problems in the

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Commonwealth are the responsibility of single offices within a state department.

The current administration of services for people with severe physical disabilities in inefficient and results in a lack of planning and coordination of services. Recent years have witnessed the establishment of new programs and initiatives for people with physical disabilities in the Commonwealth; for example, the Attendant Care Program, Independent Living Centers, the LAMP Program. As these programs become fully operational and/or expand, the potential for duplication and fragmentation will increase significantly. It is therefore timely to establish a vehicle for the planning and coordination of services for people with physical disabilities.

The need for a single state agency to assume responsibility for people with physical disabilities in Pennsylvania has been documented in previous reports and analyses. Reports by Human Services Research Institute in 1981 and 1986 pointed out that no consensus exists within the Commonwealth on where such an agency would be located. While it would be premature to recommend in this analysis where this agency should be located, the following are the major policy options:

*Location within an existing state agency (e.g., within the Office of Vocational Rehabilitation or the Office of Mental Retardation).

*Creation of a an umbrella agency to coordinate services for people with a broad range of disabilities (e.g., people with mental retardation, mental health problems, physical disabilities).

*Creation of a Commission to oversee and coordinate the operation

of programs offered by state agencies.

*Creation of a generic human service agency to coordinate services for people with disabilities and nondisabled people.

Recommendation 2A. All state departments and offices should support and cooperate with the "Comprehensive Services Objective" initiative of the Pennsylvania Developmental Disabilities Planning Council.

DDPC has issued a Request for Proposal for a Comprehensive Services Objective project to design and plan a coordinated system of services for people with disabilities. This initiative envisions a collaborative effort among state agencies, consumer and advocacy organizations, and private providers to set state responsibility for services for people with disabilities.

Since the Comprehensive Services Objective can provide a vehicle for bringing together the broad range of interests involved with people with disabilities to set future policy directions within the Commonwealth, state agencies should play an active and supportive role in this initiative.

Recommendation 3. Services for people with physical disabilities should be guided by clear state regulations, policies, and guidelines.

While recognizing that counties and local agencies must be given sufficient latitude to develop innovative and responsive services, state regulations, policies, and guidelines must be put into place to guide state-supported programs and services for people with physical disabilities. Based on this review of the Supported Housing Demonstration Project, the following stand out as major areas for

policy development:

*Consumer Control. People with physical disabilities should have the opportunity to control their own lives. This includes central involvement in the employment of attendants and/or staff and the opportunity to maintain one's own home in the community.

*Choice. Individual choice should be a guiding principle for determining where and with whom people live.

*Community Integration. People should have the opportunity to live in typical houses and apartments, with necessary architectural modifications, in neighborhoods populated primarily by people without disabilities.

*Community Participation. People should have opportunities to participate in community activities and to form relationships with other community members.

Recommendation 4. The involvement of state departments and offices in services for people with physical disabilities should be guided by formal interagency agreements.

The Supported Housing Demonstration Project was created based on informal understandings. In order to significantly expand this effort in Allegheny County or other counties in Pennsylvania, formal agreements between participating public agencies will be required.

As proposals are developed and options explored regarding the designation of a single state agency to plan and coordinate services for people with physical disabilities, interagency agreements can place programs like the Supported Housing Demonstration Project on a more secure footing and enable an expansion of community services for people currently living in nursing homes.

An example of an agreement that can be used to facilitate interagency cooperation is the recently agreed upon supported work initiative by the Office of Vocational Rehabilitation, Department of Education, and other Pennsylvania state agencies.

Recommendation 5. A stable long-term funding mechanism should be established to fund the actual costs of supporting people with physical disabilities in the community.

As documented in this report, inadequate and unstable funding exists to support people with physical disabilities in the community as an alternative to nursing homes. In view of the fact that the Supported Housing Demonstration Project can be demonstrated to be less costly than the Kane Regional Centers, it is in the interests of the Commonwealth to reallocate and channel resources to support people in the community. Current funding for services for people with mental retardation administered by the Department of Public Welfare and channelled through the counties is one example of a funding mechanism to support community living.

Recommendation 5A. Funding for services for people with physical disabilities should be guided by a conceptual framework that addresses the range of costs of living and being supported in the community.

A conceptual framework should be based on the major types of costs associated with supporting people in the community and should specify the funding sources available to pay for the costs. The following is a potential conceptual framework based on this analysis of the Supported Housing Demonstration Project:

*Housing/Household Start-Up. This includes the costs of

architectural modifications to make existing housing accessible to people with mobility impairments; furniture, furnishings, and household goods; and equipment and devices (e.g., intercom systems; Life Call/Life Line). For the Supported Housing Demonstration Project, these costs were paid through a broad range of sources including the DDPC grant, Westinghouse grant, Handicapped Challenge grant, the IMPAC grant, and LAMP funds. None of these sources can be counted on for stable funding for these expenses.

*Case Management. Ideally, case management services are independent of direct services provided to people. For the Supported Housing project, LAMP provides case management, although UCP and TRCIL staff also play a case management role.

*Adaptive Equipment. This includes wheelchairs, communication devices, and other equipment. A grant from OVR pays for these costs for the Supported Housing Demonstration Project, although delays have been encountered in obtaining necessary equipment for people.

*Medical/Health Care. This includes physician services, therapy, pharmacy services, and other health costs. The Medical Assistance program pays for these costs for people served through the Supported Housing Demonstration Project.

*Living Expenses. This includes rent, utilities, food, clothing, transportation, and personal expenses. For people served through the demonstration project, a range of income maintenance programs (e.g., SSI, SS), housing subsidies, and for people supported by UCP the Dom Care supplement supports these expenses. These

income sources are currently inadequate to cover the costs of living in the community. In addition, the Section 8 program and Dom Care supplement severely limit the selection of housing. In order to expand opportunities for people to move from institutions to the community, it is recommended that the Commonwealth fund an SSI exceptional supplement to increase housing options and cover community living expenses.

*Attendant Care. This includes the direct and administrative costs of attendants hired and supervised by people with disabilities. In the Supported Housing Demonstration Project, the Attendant Care Program pays for attendants for people supported by TRCIL and partial staffing costs for UCP. Without the Attendant Care Program neither UCP nor TRCIL clients would have been able to move into the community. While it is recommended that the Attendant Care Program continue to support both attendants for TRCIL clients and UCP staff for the Supported Housing project, as a demonstration project, it is recommended that future Attendant Care funding be limited to pay the costs of attendant services and personal assistance directly managed by people with disabilities.

*Staff Support. This includes direct and indirect costs of staff support provided to people: housing assistance; independent living counseling; training, habilitation, and rehabilitation; guidance; assistance in attendant management; and other direct staff support (e.g., personal assistance for people who do not manage their own attendants). In the Supported Housing project, costs of staff services are paid through a range of sources

including LAMP, HSDF, Attendant Care Program, and TRCIL's Transition grant. Since project funding sources do not adequately cover staffing and associated direct and indirect costs (e.g., phone, administrative costs, staff travel), these costs must be funded by the agencies themselves. It is recommended that a stable funding system be established to support direct and indirect staffing costs. Staffing costs can be supported based on flexible funding levels corresponding to the intensity of services required. For example, additional funding for staffing might be allocated to enable the Supported Housing Demonstration Project to serve people with more challenging needs.

In addition to the funding needed to support community living, funding for supported work and vocational services for people with severe physical disabilities should be considered on a policy level.

Recommendation 6. The Commonwealth should reconsider the use of Title XIX Medicaid funds to support community services for people with physical disabilities.

Several years have passed since Pennsylvania's Medicaid waiver for services for people with physical disabilities was not approved by the federal Health Care Financing Administration. In view of experience of the Supported Housing Demonstration Project and the successful use of the Medicaid waiver to support community living by the state Office of Mental Retardation, the Commonwealth should reopen the possibility of applying for a Medicaid waiver or including Personal Care as an optional Medicaid service to support community living for people with physical disabilities currently living in

institutions. Since nursing homes and similar facilities receive major Medicaid funding under the ICF and SNF programs, this serves as a disincentive to move people into the community. While the Medicaid program is not without its drawbacks, both in its medical orientation and rigid implementation by the Health Care Financing Administration, a second look at Medicaid funding to support at least some of the costs of community living for people with physical disabilities (e.g., direct staff support as opposed to attendant services) is warranted.

Recommendation 7. A single county agency should take a lead role in planning and coordinating services for people with physical disabilities on a county level.

Just as a single state agency must take a lead role in planning and coordinating services for people with physical disabilities on a state level, there is a need for a single agency to take responsibility for the planning and coordination of services on a county level. In mental retardation and mental health, state funding is funneled through a single county department, which contracts with local providers to operate services. In the area of community services for people with severe physical disabilities, responsibility at the county level is unclear. In Allegheny County, for example, while LAMP provides assessments and case management and funds some community services as an alternative to nursing home placement, it lacks a clear mandate to plan and coordinate services within the county. Further, while funding for community services comes from several state departments, LAMP holds contracts with the Department of Aging. Whether LAMP or another county agency assumes

responsibility for community services at the county level should depend on how responsibility is set on the state level.

Recommendation 8. Counties should consider a direct allocation of resources to support community services for people with severe physical disabilities.

While the Supported Housing Demonstration Project is supported primarily by state and federal funding sources, the budget of the Kane Regional Centers receive a substantial level of county funding. In view of the lower costs of the demonstration project vis-a-vis facilities like the Kane centers, in addition to its benefits in human terms, it is in the interest of counties to allocate funding directly to community services. Of course, funding might come from either new allocations or a diversion of funds allocated to institutions.

In conclusion, the direction set by the Supported Housing Demonstration Project is deserving of state and county support in terms of both policy and resources.

People with severe physical disabilities--people with traumatic brain injury, spinal cord injury, severe cerebral palsy, multiple sclerosis, and similar disabilities--are a classic example of a population that "falls through the cracks" of the service system. In Allegheny County, a group of committed individuals and agencies have come together to attempt to fill some of those cracks for some of that population. Their experience supports the case for closing those cracks for good.

APPENDIX: METHODOLOGY

This analysis of the Supported Housing Demonstration Project was conducted between October, 1986 and May, 1987 and included three sites visits to Allegheny County, Pennsylvania.

The purpose of the analysis was to review the operation of the project and to examine the project's policy implications. Specific attention was devoted to the administrative, programmatic, and fiscal aspects of the program.

The analysis was based on on-site interviews and observations, phone interviews, and a review of documents and written materials. All interviews and observations were based on an open-ended, qualitative research approach (Steven J. Taylor and Robert Bogdan, An Introduction to Qualitative Research Methods. New York: John Wiley, 1984).

The analysis was based on the following specific activities:

1. Indepth interviews with administrators and supervisory staff at UCP of Pittsburgh.
2. Indepth interviews with administrators and program staff at Three Rivers Center for Independent Living.
3. Interview with the administrator of Scott Kane.
4. Meeting with the LAMP Subcommittee on the Supported Housing Demonstration Project.
5. Interviews with four UCP program staff and less formal discussions with four additional program staff.
6. Interviews with five residents of Allegheny Independence House who receive support from Three Rivers

Center for Independent Living.

7. An interview with a resident of a apartment high-rise who receives support from Three Rivers.

8. Interviews with seven residents of the UCP cluster apartments.

9. Observations of Allegheny Independence House.

10. Observations of UCP apartments at Versailles Castle and Lindenbrooke clusters.

11. Review and analysis of program descriptions prepared by LAMP, UCP of Pittsburgh, the Kane Regional Center, and Three Rivers Center for Independent Living.

12. Review and analysis of program budgets of UCP of Pittsburgh.

13. Review and analysis of state policy/evaluation reports prepared by The Conservation Company (A Final Report of an Evaluation of the Pennsylvania Attendant Care Demonstration Project: Volume I. October 1986) and Human Services Research Institute (Report on the Habilitation Services Objective, November 1981; and A Policy Analysis of Attendant Services in Pennsylvania, May 1986).

14. A review of cost information on the Kane Regional Centers contained in a letter dated April 1, 1987 from James J. Goodrich, Associate Executive Director for Fiscal Services, Kane Regional Centers Central Administration.

15. A review of documents relevant to the project prepared by the Pennsylvania Developmental Disabilities Planning Council.

16. Interview with the Controller of UCP.

17. Interview with the Controller of Three Rivers Center for Independent Living.

18. Phone interviews with three state officials and one county official familiar with the project.

In addition, this analysis draws on information gathered through an ongoing study of the state of the art in community living for people with severe disabilities funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education.

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